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ABSTRACT

This collection of articles evolved from papers presented and issues discussed at a workshop entitled "The Health Care/Education Relationship: Services for Infants with Special Needs and Their Families," held in March, 1981, for members of the Handicapped Children's Early Education Program (HCEEP) network. During that workshop, staff from many HCEEP projects involved with neonates and their families came together to share information regarding the problems and developments of professionals in health care environments. Grouped into the larger categories of assessment, intervention, and family support, chapters provide information on significant and innovative practices currently being used and tested in the field of neonatal care. Part 1 includes papers by leading researchers in the field, including Brazelton, Als, and Duffy. Part 2 focuses on the evolving role of the infant developmental specialist. Part 3 includes papers which discuss innovative approaches to fostering positive interactions between professionals and the families of hospitalized infants. (RH)

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Issues in Neonatal Care

Edited by Arnold Waldstein
David Gidderman • Denise Taylor Hershel
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FOREWORD

In each decade of this century there have been significant reductions in infant mortality, particularly in the first four weeks of life, the neonatal period. This has been due to constantly improving medical care of mothers during pregnancy, mothers and infants during labor and delivery, and of infants after birth. The most dramatic reduction in neonatal mortality has been since 1970 with a drop in mortality from 15.1 per 1000 in 1970 to 8.4 in 1980¹. Most of the improvement in mortality rates during this period was due to the development of the intensive care nursery (ICN).

The first predecessor to the modern ICN was a premature "station" started in 1922 at the Sarah Morris Hospital in Chicago with specially trained nurses and incubators for keeping the infants at normal body temperature. However, the growth of the modern ICN has not been constant. In the early 1930's the majority of hospitals still had no special facilities for preterm infants. Chicago established the first city-wide program for premature infants in 1934 and some state-wide programs were developed after the Social Security Act of 1935 provided funds for maternal and child health. But it was not until 1962 that the first modern neonatal intensive care units were started. By 1970 they were widely distributed throughout the country.

The changes in survival rates for the smallest preterm infants illustrate the importance of the changes in nursery care in the ICNs. In New York City in 1950 the reported survival rates for preterm infants with birthweights of less than 1000 grams was 9% and 50% for birthweights of 1000 to 1500 grams². Currently, preterm nurseries in New York are reporting survival rates of 62% for infants with birthweights of 500-1000 grams and 85% for those with birthweights of 1000-1500 grams³.

With the improved survival rate of sick newborn infants, particularly small preterm infants, there has come some apprehension concerning the quality of life of the survivors. The infant survivors are commonly labeled "infants at-risk." As a group they have a higher incidence of motor, sensory and other developmental problems than healthy full-term newborn infants. However, the degree of risk for some types of disabilities for these infants is not clear, nor do we know precisely the factors that combine to put some infants at greater risk than others.

¹Wegman, M. Annual summary of vital statistics: 1980. *Pediatrics*, 1981, 68, 755-762.

²Hess, J.H. Experience gained in a thirty year study of prematurely born infants. *Pediatrics*, 1953, 11, 425-434.

³James, L.S. Outcome following newborn intensive care. Presentation to the Los Angeles Pediatric Society, January 1981.

In practically every longitudinal study of infants at-risk for biological reasons, social factors have nevertheless been dominant determinants of outcome. There is evidence suggestive of an interactional effect; it seems that the greater the biological risk, the more optimal the environment needs to be to promote the best outcome for the child. This does not mean that a supportive environment can overcome an acute medical problem such as cerebral palsy, severe retardation or blindness, but it can help the family maximize the development of such children. It may mean that lesser degrees of neurological problems can be functionally overcome in a supportive environment. It clearly does indicate that adverse environments can interfere with normal development.

Current research into normal and abnormal infant development, attachment behaviors and the factors which contribute to or detract from successful parenting are modifying our conception of infant intervention. The form and style that intervention should take is still under investigation. If, as seems likely, both parents and at-risk infants are best served by a coordinated intervention approach which minimizes the detrimental effects of a large number of caregivers, there still remains the question of who should take the lead in the ICN setting. It seems likely that in the future, coordination will increasingly become the responsibility of a professional known as the infant developmental specialist. The specialist will counsel parents, assess and develop curricula for infants from birth to nursery school age, coordinate and transmit all the information and skill from the various consulting disciplines to parents and incorporate it into their work with the child.

This new professional field has already begun to evolve; there are infant developmental specialists now working very effectively. They have come from many disciplines and have trained themselves in infant development and parent counseling. Each tends to bring with him or her a strong emphasis from a basic discipline such as physical therapy, nursing, social work, speech therapy, psychology, pediatrics, psychiatry or education. What is needed now is coordination between all the disciplines involved in the training of infant developmental specialists and a sharing of knowledge, research and experiences about intervention programs for newborns and young infants and their families. This book is an important step in that direction.

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INTRODUCTION

This monograph is an outgrowth of a workshop titled "The Health Care/Education Relationship: Services for Infants with Special Needs and Their Families," held in New Orleans in March 1981 for members of the Handicapped Children's Early Education Program (HCEEP) network. During that workshop, staff from many HCEEP projects that work with neonates and their families came together to share information regarding the problems and developments of professionals in health care environments. The chapters included here are expansions of the papers and issues presented during that workshop. They provide information on some of the most significant, innovative practices currently being used and tested in this field.

The field of neonatal care has been evolving rapidly over the last 10 years and is still in a period of expansion and change. New theories of infant development are being elaborated and research initiated, new professional roles are emerging, services are expanding, and technological advances are being made. The chapters in this book address changes in each of these areas.

Advances in the field, as Parmelee and Howard have noted in their Foreword, have contributed to a significant decline in infant mortality. The National Institute of Child Health and Human Development¹ reports that infant mortality during the first year of life has decreased by 31% and that neonatal mortality has decreased by 37.1%. However, the risk factor for premature infants is still extremely high. On an average, one-quarter of all infant deaths are accountable to premature births.

As many of the writers in this monograph mention, in work with premature and seriously ill neonates, survival is the overriding concern; yet it is not the only concern. The fragile infants admitted to the intensive care nursery are not only more likely to die, they are also more likely to suffer sustained, long-term developmental problems. Researchers report that the incidence of handicapping conditions for low birthweight infants is at least 10%² and that 60% of surviving premature infants may experience learning disabilities or cognitive and physical handicaps by eight years of age³. Although the specific causes and

¹National Institute of Child Health and Human Development. Child health and human development: An evaluation of the state of the science (Vol. II, Pregnancy, Birth, and the Infant). Bethesda, MD: National Institute of Health, 1981.

²Fitzharding, P.M. Follow-up studies on the low birthweight infant. Clinical Perinatology, 1976, 3, 503-516.

³Kitchen, W.H., Ryan, M.M., Rickards, A., McDougall, A.B., Billson, F.A., Keir, E.H., & Naylor, F.D. A longitudinal study of very low birthweight infants: An overview of performance at eight years of age. Developmental Medicine and Child Neurology, 1980, 22, 172-188.

treatments of such latent handicapping conditions have not yet been fully researched and identified, a correlation of prematurity with the incidence of a handicapping condition is firmly established.

Coincident to the health care issues raised in this book are the ethical considerations which surround the giving or withholding of life-supporting care to seriously ill neonates. Involuntary euthanasia with its wide spectrum of moral, medical and legal dilemmas will increasingly become an important aspect of neonatal care. This topic, although beyond the scope of this book, is one that must be confronted by families, medical and educational personnel, and the legal system.

The chapters of Issues in Neonatal Care are arranged into three parts, each addressing a subject of primary importance to professionals who work in the ICN: Assessment, Intervention and Family Support.

The first part, Assessment, includes papers by leading researchers in the field. Dr. T. Berry Brazelton, the well-known pediatrician and originator of the Brazelton Neonatal Behavioral Assessment Scale (BNBAS), has contributed a chapter titled "Assessment in Early Infancy as an Intervention." In it, he discusses the potential negative effects of risk births on the parent/infant relationship and describes his successful use of the infant assessment as a means of entering this relationship at a critical early stage to mitigate those effects. The second paper, "The Behavior of the Fetal Newborn: Theoretical Considerations and Practical Suggestions for the Use of the APIB," is by Drs. Heidelise Als and Frank Duffy, colleagues of Dr. Brazelton's at the Children's Hospital Medical Center at the Harvard Medical School in Boston and developers of the Assessment of Premature Infants' Behavior Scale (APIB). They elaborate on the synactive theory of development which informs both Dr. Brazelton's work and their own, and they describe their work with the APIB as it substantiates and expands upon that theory.

Part II, Intervention, focuses on the evolving role of the Infant Developmental Specialist. Nancy Sweet, Director of the ICN Interact Project at the Children's Hospital Medical Center in Oakland, California examines the variable components of nursery intervention programs and delineates philosophies of intervention in the intensive care nursery (ICN). Her paper, "New Faces and Approaches in the Intensive Care Nursery: The Role of the Developmental/Educational Specialist," shows how the specialist in her program functions within the highly technical reality of the ICN. The second paper in this section, "Humanizing the Intensive Care Nursery," is written by Kathleen VandenBerg, the Infant Educator from the ICN Interact Project. She analyzes the stresses of the ICN environment and shows how they affect infants, parents and nurses. She demonstrates how developmental intervention can lessen some of these inherent stresses. The third paper in this section is by Jean Cole and Linda Gilkerson of Project WELCOME in Boston. In their paper, "Developmental Consultation: The Role of the Parent/Infant Educator in a Hospital/Community Coordinated Program for High-Risk Premature Infants," they outline Project WELCOME's conception of the educational specialist's role in the ICN and show how a care system for premature infants functions under a developmental consultation model.

The final section of the book, Family Support, includes three papers which discuss innovative approaches to fostering positive interactions between professionals and the families of hospitalized infants. The first paper is by Mary Cerreto, an Associate Professor of Pediatrics at the University of Texas and Vicki Switzer of Vanderbilt University. Their paper, "Range of Family Supports: The Effects of Hospitalization on Siblings," suggests ways to work with the siblings of hospitalized and handicapped infants. The second paper, "Clinical Realities of the Attachment Process," is by Richard Iacino, an Assistant Professor of Pediatrics, from the Mailman Center at the University of Florida. In it, he questions the current conception of bonding and examines the possible effects of differing cultural backgrounds on the attachment process. The final paper, by Ronald Schmerber, "Communication Strategies with Parents," describes the approach to parental services developed by the Pre-Start Program for families of preterm and high-risk infants in Maywood, Illinois.

In the coming decade, as in the last, many issues will demand the attention of professionals in the field of care for premature infants and their families. Issues in Neonatal Care offers a significant contribution to this rapidly changing field. TADS and WESTAR hope that this monograph will be of use to all individuals who work with preterm and seriously ill infants. Furthermore, it is hoped that by sharing these new practices and discussing the problems of caring for this population, the situation of preterm infants will be improved and that the often devastating impact of such children on their families will be lessened.

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Assessment



ASSESSMENT IN EARLY INFANCY AS AN INTERVENTION*

T. Berry Brazelton

The increasing capacity of medicine for conquering physical disease has made it possible for educators and medical personnel to concentrate on the prevention of physical and psychological disorders and the mitigation of their effects on the quality of life of affected individuals. This in turn has helped bring about an attitudinal change towards handicapping conditions. "Prevention," "intervention" and "quality of life" have become catchwords for disciplines concerned with medical and psychological disorders. "Plasticity," the capacity of a developing organism to find pathways around a deficit, has dawned upon many researchers and clinicians as if it were a new concept and likewise has enlarged the parameters of medical and educational treatment for at-risk or handicapped infants.

The evidence for plasticity in infants is impressive. The remarkable ability of a child to recover from established central nervous system (CNS) deficits is being found in many longitudinal studies of high-risk infants. Children with known insults and identified defects in CNS tissue seem to be able to compensate for these deficits over time (Neligan, Kolvin, Scott, & Garside, 1976; Sigman & Parmelee, 1979). With a defect such as blindness, for example, the child can learn to compensate with increased sensitivity of the other senses--auditory, tactile and vestibular. An instance of this is the "radar vision" that was marked by heightened sensitivity to auditory cues in a 14-month-old blind baby, who vocalized as she walked and never ran into tables, who rounded corners of doors by the differences in reverberations as her vocalizations bounced off nearby objects (Als, Tronick, & Brazelton, 1980).

A recent longitudinal study by Sigman and Parmelee (1979) has shown that the best predictors for the compensatory recovery of CNS deficits rest in 1) the energy of the infant to reach out for and interact with the environment (as reflected by visual behavior at one month), and 2) the richness of environmental input available to the infant as it was measured at four months (Sigman & Beckwith, 1980). This points to a model which involves 1) maturation, 2) an inner

*This paper is a revised form of the chapter, "Early intervention: What does it mean?" In H. E. Fitzgerald, B. M. Lester & M. W. Yogman (Eds.), Theory and research in behavioral pediatrics. New York: Plenum Press, in press, 1982. Any quotes from this transition should credit the original chapter cited above, with the approval of the author and first editor.

source for fueling compensatory and rewarding developmental systems, and 3) a rewarding environment which reinforces both specific compensatory behaviors and a more general sense of achievement as each developmental step is reached and achieved. When the environment fails to provide these rewards, this may add further to developmental failure in the infant.

This paper presents such a model, along with a discussion of the forces in both the infant and the parent that can work toward optimal recovery of the high-risk or damaged infant. It traces the role that infant assessments can play in successfully utilizing those forces. The content is derived from our work with the Neonatal Behavioral Assessment Scale (NBAS) (Brazelton, 1973) and the face-to-face paradigm, both of which have proven to be revealing windows into normal infant development, as well as powerful intervention tools.

CRITERIA FOR SUCCESSFUL INTERVENTION

Recent long-term follow-up studies indicate that certain ingredients are critical to the success of infant intervention programs (Sigman & Parmelee 1979). The intervention must be of a quality which fosters both the sense of competence of the developing child and the child's own energies for learning to cope. It must be accompanied by energy in the environment to back up the child's efforts at compensatory learning. Successful intervention must also be based on an understanding of the normal forces for development in the infant and of the forces for attachment and grieving in the caring parents. The timing of intervention is as critical as the quality, not only in terms of strengthening the infant's assets to overcome deficits, but also in reinforcing a positive self-image from the first and adding motivation toward recovery or optimal functioning. As the potential for early intervention increases, it becomes more and more important that we be able to evaluate at-risk infants as early as possible, with an eye to more sophisticated preventive and therapeutic approaches, before failure systems and the expectation to fail gets built in. Early intervention, properly and conscientiously administered, may prevent a compounding of problems which occur all too easily when the environment cannot adjust appropriately to the at-risk infant.

Premature and minimally brain-damaged infants seem to be less able to compensate in disorganized, depriving environments than do well-equipped neonates, and so their problems of organization in development are compounded extremely early in life (Greenberg, 1971). For example, quiet, non-demanding infants do not elicit necessary mothering from already overstressed parents. In poverty-ridden cultures such as in Guatemala and Mexico, they are selected by their neonatal behavior for kwashiorkor and marasmus* (Brazelton, Tronick, Leghtig, Lasky, & Klein, 1977; Cravioto, Delcardie, & Birch, 1966). On the other

*Kwashiorkor is a severe nutritional deficiency affecting infants in their second year and usually associated with being weaned or having an infection during the second year. Marasmus is also a condition of severe undernutrition, usually occurring in the first year. In the USA, marasmus is referred to as "failure to thrive" syndrome and is often the result of a failure in the environment to provide emotional or nutritional nurturance.

hand, hyperkinetic, hypersensitive neonates may press a mother and father into a kind of desperation. The parents' responses then reinforce their children's problems, engendering an overreactive, hostile environment for the child which is detrimental to development (Heider, 1966).

Parents of children admitted to the wards of the Children's Hospital in Boston for such clinical syndromes as failure to thrive, infantile autism, child abuse and repeated accidents and ingestions are often successful parents of other children. By history, they associate their failure with this child with an inability to "understand" him or her from the neonatal period onward, and they claim a difference from the other children in this child's earliest reactions to them as parents. If we are to improve the outcome for such children, assessment of the risk in early infancy could mobilize preventive efforts and programs for intervention before the neonate's problems were compounded by an environment which could not understand them without such help.

Another critical aspect of intervention is individuation. Programs which are individuated--orientated toward the needs of a particular baby--have the possibility of reaching out to the target individuals in a way that will allow them to feel "special." Not only will the intervention be more likely to suit particular needs, but the very effort to understand those needs will create a kind of Hawthorne effect--a feeling of "being special" and important to others, hence to oneself. Individuation of programs and an attempt to make the targeted individuals feel they are in control of their own destiny are critical to achieving optimal results.

In contrast, oversimplified, non-individuated programs of intervention may do more harm than good. One example can be found in the widespread stimulation programs which are designed to correct identified deficits in development. Frequently in these programs, lower socio-economic status groups are targeted with middle-class therapists' goals. Since the risk for developmental failure seems often to be associated with lower socio-economic status environments (Neligan, et al., 1976), this may appear to be an appropriate intervention goal. But one wonders whether the goals of the therapist can match those of the recipient in such programs, and whether the risk of failure in basic communication may not reinforce the sense of failure already endemic among lower-class recipients. If the inability to understand or comply with the intervention is added to the sense of failure in those around the infant, the parent's self-image is bound to be affected. Hence, the efforts of well-meaning professionals may compound the failure in caring parents who cannot reach the standards set for them.

Unless we as professionals understand the processes which contribute to the risk for failure, as well as those which promote plasticity or recovery from the deficit, we cannot begin to play an appropriate role in enhancing recovery in the infants themselves. And, unless we can understand the interactive processes between each individual parent and infant, we are not likely to enhance the environment's role in fueling that recovery.

Infant assessments have become a valuable tool toward meeting these criteria. We have learned much about their uses through our work with the Neonatal Behavioral Assessment Scale (NBAS) and our face-to-face assessments of parent-infant interactions. The assessments have served as a way of

identifying with individual infants and their parents, and as a means of helping the parent to believe in and work toward the baby's own best potential. Through our face-to-face assessments, we have come to realize the potency of violations of expectancy in distorting parent-infant interactions and have appreciated the consequences, in such interactions, of parental grief. The use of repeated assessments as recovery curves has taught us to understand the processes of recovery in early infancy beginning with labor and delivery, and it has given us a way to assess and enhance the input from the environment, even in the face of CNS or autonomic nervous system defects.

FORCES FOR NORMAL DEVELOPMENT IN THE INFANT

An understanding of the forces which work toward a child's development is critical to an understanding of the child's failure and toward any effort to prevent such failure. There are at least three forces that are constantly at work:

1. Maturation of the central and the autonomic nervous systems which regulate babies' capacity to control their reactions to incoming stimuli. As their nervous systems mature, babies are increasingly freed to interact with their environment. If infants are at the mercy of an overreaction of either a motor (Moro or startle) or autonomic reaction (as seen in an overstressed pulmonary or cardiac system), they cannot learn to maintain attention or to react appropriately to a sensory stimulus or other information necessary to their development.

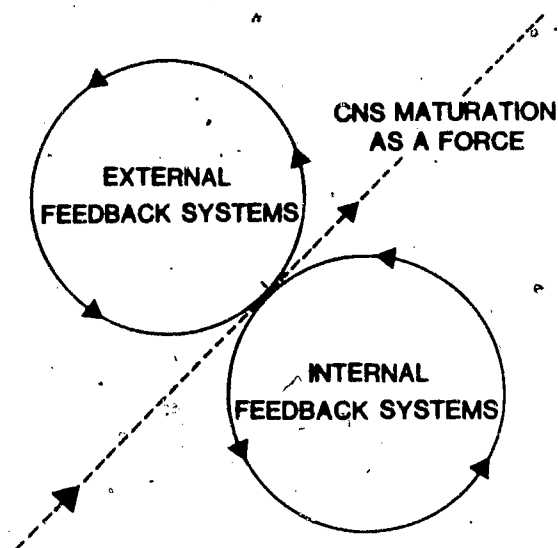
2. Forces of competence within children which are enhanced by a feedback system that relies upon the completion of a task that they themselves have done. Robert White (1959) called this a "sense of competence," and one sees its power as a source of fuel when toddlers first learn to walk--the face glows, the body struts, the legs are driven to perform for long, exhausting periods; the toddler chortles with delight in the achievement. The energy which has been mobilized to complete the task now fuels the realization of mastery and, in turn, is reinforced to press the child on to the next step in development. In hospitalized or institutionalized children who do not have the opportunity for completing new developmental tasks, one sees the waning of this kind of inner excitement (Provence & Lipton, 1962).

3. Reinforcement from the environment around infants which feeds their affective and cognitive needs. The feedback cycles which are necessary for normal affective growth were first pointed out by Spitz (1945) and later by Harlow (1959) in monkeys and then were conceptualized as "attachment" by Bowlby (1969). That this affective base is critical to cognitive and motor development was well documented in the institutionalized infants of Provence and Lipton (1962). Only when the pathology was identified in environmentally deprived infants did we fully understand the importance of environmental nurturance in all facets of an infant's development. Environmental forces can work powerfully to retard or to enhance the infant's progress. In our lab, we are attempting to identify and conceptualize some of the ingredients of these interactive forces as they combine to fuel the child's recovery from prematurity, respiratory distress syndrome and CNS deficits.

These forces are graphically illustrated in Figure 1.

Figure 1

Three Sources of Energy for Development



DEVELOPMENTAL MODEL

When we began in the early 1950s to document and understand neonatal behavior, we found that it seemed to be dominated by very powerful mechanisms (Brazelton, 1961). The changeover from intrauterine to extrauterine existence demands a tremendous physiological realignment, and it has always amazed us that there is any room for individualized responses; for alerting and stimulus-seeking, or for behavior which indicates a kind of processing of information in the neonate; and yet there is. Despite the fact that the infant's major job is that of achieving homeostasis in the face of enormous onslaughts from the environment, we can see evidence of affective and cognitive responses in the period immediately after delivery.

This very capacity to reach out for, to respond to and to organize toward a response to social or environmental cues seems so powerful at birth! One can see that even as newborns, infants are "programmed" to interact; as they wake from sleep and are on their way to a disorganized crying state, they turn the head to one side to set off a tonic neck reflex and adjust to this with a hand-to-mouth reflex and sucking on the fist. All of these can be called primitive reflex behaviors. But as soon as newborns have completed this series, they sigh, look around, and listen with real anticipation, as if to say, "This is what I'm really here for--to keep interfering motor activity under control so that I can look and listen and learn about my new world."

Our own model of infant behavior and of early infant learning builds on progressive developmental stages. Infants are equipped with reflex behavioral responses which are established in rather primitive patterns at birth. The infants soon organize them into more complex patterns of behavior. These in turn serve as goals for organization at a time when infants are still prone to a costly disorganization of neuromotor and physiological systems, and later for attention to and interaction with the world (Als, Lester, & Brazelton, 1979). Thus, infants are set up to learn about themselves; for as they achieve each goal, their feedback systems say, "You've done it again! Now go on." In this way, each time they achieve a state of homeostatic control, they are fueled to go on to the next stage of disruption and reconstitution--a familiar model for energizing a developing system. We also believe that the infants' quest for social stimuli is in response to their need for fueling from the world outside. As they achieve a homeostatic state, and as they reach out for a disruptive stimulus, the reward for each of these states of homeostasis and disruption is reinforced by social or external cues.

Hence, infants start out with the behaviorally identifiable mechanisms of a bimodal fueling system: 1) attaining a state of homeostasis and a sense of achievement from within, and 2) the energy or drive to reach out for and incorporate cues and reinforcing signals from the world around them, thus fueling them from without. They are set up with behavioral pathways for providing both of these mechanisms for themselves, for adapting to their new world, even in the neonatal period. Very little fueling from within or without may be necessary to "set" these patterns and press the child onward, so they are quickly organized and reproduced over and over until they are efficient and incorporated and can be used as the base for building later patterns. Greenacre's (1959) concept fits such a model: it is that early pathways for handling the stress and trauma of birth and delivery are precursors for stress patterns later on. It seems that patterns or pathways which are effective are "greased up" for more efficient use later in life. Our own concept is that other patterns are available too, but that these are just readied by successful experience.

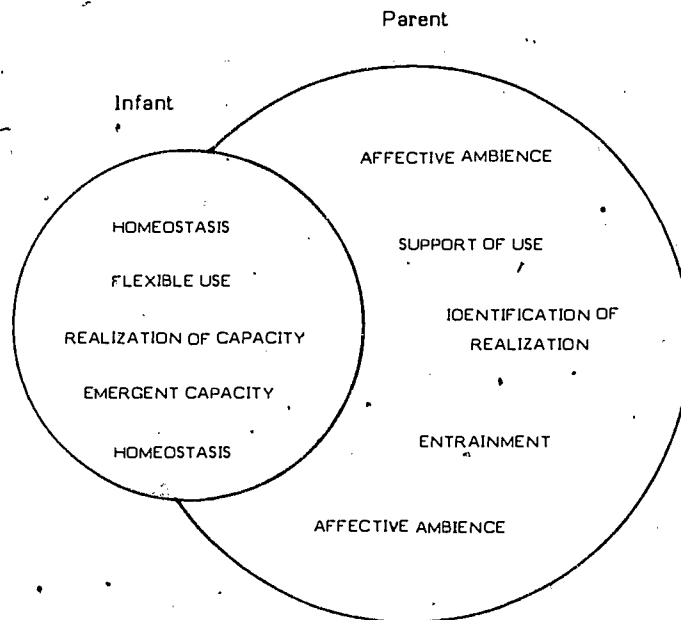
The same model can incorporate Sander's (1977) ideas of early entrainment of bio-behavioral rhythms, Condon and Sander's (1974) propositions that the infant's movements match the rhythms of the adult's voice, Meltzoff and Moore's (1977) work on imitation of tongue protrusion in a three-week-old infant, and Bower's (1966) observations on early reach behavior to an attractive object in the first weeks of life. As each of these responsive behaviors to external stimuli fuels a feedback system within infants toward a realization that they have "done it"--controlled the self in order to reach out for and respond appropriately to an external stimulus or toward a whole adult behavioral set--they get energized in such a powerful way that one can easily see the basis for entrainment. The matching of one's responses to those in the external world must feel so rewarding that the infants quickly become available to whole sequential trains of behavioral displays in the environment and begin to entrain with them. They become energized to work toward inner controls and toward states of attention which maintain availability to these external sequences.

From the simpler form of attention to discrete stimuli, infants are able to move toward prolonged periods of attention. These periods are marked by sequential reactions to each stimulus. The sustained attention is modulated by brief but necessary periods of decreased attention. In this way, a homeostatic curve of attention-withdrawal (and recovery) becomes the psychophysiological base for entrainment with a series of stimuli.

This, of course, is more complex than a simple stimulus-response system. In this model, entrainment becomes a larger feedback system which adds a regulating and encompassing dimension to the two systems of internalized control and externalized stimulus-response. It is an envelope within which infants can test out and learn about both of their fueling systems. According to this model, infants thus can learn most about themselves by making themselves available to entrainment by the world around them. This explains the observable drive on the part of neonates to capture and interact with an adult and their need for social interaction. Figures 2 and 3 show a schematic presentation of this mutual fueling process (Brazelton & Als, 1978; Als, 1979).

Figure 2

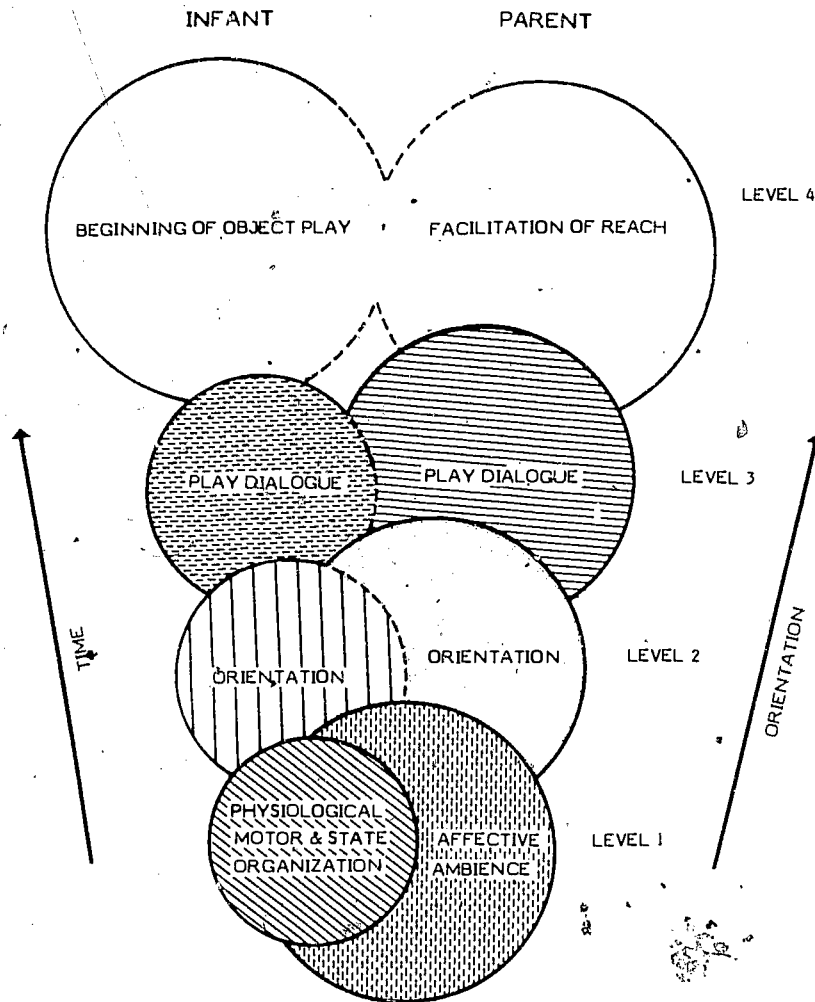
Process of Interactive Negotiation Bringing About
Each Stage of Organization



Note. Reprinted by permission of Yale University Press from Brazelton, T.B., & Als, H. Four early stages in the development of mother-infant interaction. In The Psychoanalytical Study of the Child, 1979, 34, 349-369.

Figure 3

Stages of Organization
Parent Infant Interaction



Note. Reprinted by permission. Als, H. Social interactions: Dynamic matrix for developing behavioral organization. In I.C. Uzgiris (Ed.), Social interaction and communication during infancy: New directions for child development, (Vol. #4). San Francisco, CA: Jossey-Bass, 1979.

FORCES AFFECTING THE PARENT

Parents, of course, play a critical role in this developmental model. They control, to a large extent, the environmental input that their infant receives; they are the primary partners in the infant's social interactions.

The parents' own potential for success in these interactions is influenced by past experiences, and these form the most powerful base for their capacity to nurture a new baby. Healthy parents, who have been nurtured as children, can be expected to mobilize resources to adapt to the individual baby. However, parents who are stressed--who are themselves afflicted with physical or psychological deficits, for example--may not be able to do so. Their capacity to adapt to the needs of an individual baby may well be dominated by their own needs and their own past experience. In groups whose energy (both physical and psychological) is limited by the demands of poverty and its concomitants--disorganization, undernutrition, a sense of failure--it is no wonder that we find limitations on parents' ability to adapt to the individual child, especially if the child is not rewarding or has special needs. It is no surprise that socio-economic status is one of the most important marker variables in predicting the recovery of children at-risk for all conditions both physical and psychological (Drillien, 1964; Neligan, et al., 1976).

What is surprising is that there is energy in most parents to adapt to a new baby and how available this energy can be. In order to understand the forces for adaptation to a new baby at delivery and in the immediate perinatal period, we studied a group of primiparous mothers in psychoanalytic interviews in the last months of pregnancy at the Putnam Children's Center in the 1950s. We found that the prenatal interviews with normal primiparas uncovered anxiety which seemed to be of almost pathologic proportions. The unconscious material was so confused, so anxious and so near the surface, that before delivery one doubted the woman's capacity to adjust to the role of mothering. Yet when we saw her in the postpartum month as a mother, this very anxiety and the distorted unconscious material seemed to have become a force for reorganization and for readjustment to an important new role (Bibring, Dwyer, & Valenstein, 1961; Brazelton, 1963). I began to feel that much of the prenatal anxiety and distortion of fantasy were healthy mechanisms for bringing the primiparous mother out of her old homeostasis to a new level of adjustment. The "alarm reaction" we were tapping in on was serving as a kind of "shock" treatment for reorganization to a new role. I now see the shakeup in pregnancy as readying the circuits for new attachments, as preparation for the many choices which the mother of a neonate must be ready to make in a very short, critical period, and as a method of freeing her circuits for a kind of sensitivity to the infant's individual requirements. The very emotional turmoil of pregnancy and of the neonatal period can be seen as a positive force for the mother's healthy adjustment and for the possibility of providing a more individualizing, flexible environment for the infant (Bibring, et al., 1961). (The pain can also be viewed as a preparation for the detachment that later becomes necessary to the baby's developing autonomy.)

FORCES FOR FAILURE IN THE INTERACTION

The pressures on parents, both internal and external, to succeed with their infant can work for failure. When parent-infant feedback systems are not being completed in an expected way, the impact on both parents and infants can be very powerful (Tronick, Als, Adamson, & Brazelton, 1978). Social interaction appears to be a rule-governed, goal-oriented system in which both partners actively share from the very beginning. Even very young infants can be profoundly affected by the violation of their expectancy in interactions. We have found the best example of this in the "still-face condition" as observed in our laboratory. In this instance, mother and infant are engaged in a face-to-face play situation, but the mother is told to remain alert and unresponsive. This violates the expected social interaction by conveying contradictory information about one partner's goal or intent. The mother, by her entrance and en face position, is initiating and setting the stage for an interaction, but then her lack of response indicates a disengagement or withdrawal.

An infant's recognition of the mother's violation of reciprocity in the still-face condition begins very early. Along with Stechler and Latz (1966) and Carpenter (1974), we have seen evidence of it as early as two to three weeks of age. It is clearly established by four weeks, and the responses produced by it become increasingly complex as the infant matures. For instance, a three-month-old infant began reacting to the still face by showing the characteristic wary pattern of behavior. About a minute and a half into the interaction, he looked at his mother and laughed briefly. After this brief, tense laugh, he paused, looked at her soberly, and then laughed again, loud and long, throwing back his head as he did so. At this point, the mother became unable to maintain an unresponsive still face, broke into laughter, and proceeded to engage in normal interactional behavior. (The intentions and emotions of the older infant are similar to those of a younger infant. Their richness and skill in reestablishing a reciprocal interaction, however, are greater.)

The strategies that this infant employed to bring his mother out of her immobility demonstrates his growing confidence in his effectiveness as a social partner. The seriousness of his reaction when the mother remained unresponsive demonstrates how critical reciprocity is to him. When infants are unable to pull their mother into the interaction and finally withdraw, they remind us of the withdrawn behavior and huddled postures of isolated monkeys (Harlow & Zimmerman, 1959) and of Bowlby's (1973) description of the withdrawn behavior of children separated from their caretakers.

The still-face mothers in our study remained unresponsive for only three minutes, yet their infants found even such a temporary violation greatly disturbing. This suggests that reciprocity and mutual achievement of the goals of social interaction form a necessary basis for the growth of affective well-being in early infancy.

Parents, too, are deeply affected by failures of expectancy in parent-infant interactions. The vulnerability of the parent to even mildly distorted cues from the infant can best be understood in the light of a "grief reaction" in the parent.

The very energy which has been mobilized to relate to a baby can turn into grieving in such cases.

The forces for grieving, as described by Lindeman (1944) in his studies of adults who experienced an unexpected loss of a loved one at the time of the Coconut Grove fire, were those of overwhelming despair, self-incrimination and guilt. Expected mechanisms, in this instance, were those of feeling guilty at not having "cared enough." The self-incrimination and depression were so intolerable that they gave rise to defenses of denial, projection of guilt onto others, and detachment from the loved one. These feelings and the defenses are common to all parents of a damaged or sick infant.

Denial is a mechanism used to handle the violations of expectancy in behavior and in responsiveness. Parents deny that these violations matter, thereby covering up for themselves and for others how deeply affected they really are by the inadequate responses they are receiving. Projection is a common mechanism also. Parents project onto those around them the inadequacy they feel about having produced such a baby and about their inability to care for the baby properly. By projecting these feelings onto others, they can tolerate them better in themselves. But this very projection makes the parents less available for interaction with a helping person. Detachment is an understandable response in that the caring parents, who believe they have already damaged the infant, feel that if they were out of the way or detached, the infant might be less at risk. This also serves to make parents less available to the infant.

All of these forces of grief are foreseeable and normal. They must be expected and dealt with if one is to capture the nurturant forces in the parent necessary to enhance the infant's recovery. If the parents' resources are turned inward in the grieving process, they become encapsulated and defenses become strengthened. The result is to turn available energy away from the baby. In the period of acute grieving, this self-protective mechanism may be necessary. At the point where the reorganization of the parents' ego has been accomplished, this energy can be made available toward the baby's recovery (Greenberg, 1979).

It has constantly surprised us that, even in the face of a devastating diagnosis of retardation, a parent can have the energy available to search for and work with the more hopeful, positive behaviors of the baby. For example, parents of babies with Down's Syndrome can work to achieve an interactive alert state in the baby, and, within this state, they can teach the afflicted infant to achieve remarkable developmental steps. Unless parents can be captured to turn their grieving around, to turn its energy outward in the service of the child's best recovery, the chance is good that they can remain permanently withdrawn and unavailable to an at-risk child. The job of the interventionist is to accept the negative forces of grieving, and to work to free up positive forces for interaction with the child as well. This work is best done if it is done early and if it utilizes the best behaviors in the child as a demonstration to capture hope and reciprocity in the parents.

Anyone interested in intervention must understand in parents the process and defenses of grief as well as those of attachment. He or she must also understand the processes of behavioral reactions, their violation and the potential for recovery in the baby. This is a large order.

IMPORTANCE OF ASSESSMENT OF THE INFANT

Both parents and infants have innate energies which can work toward recovery and optimal function of the high-risk child. It is the task of intervention programs to harness and direct these forces. Infant assessment can play a very important role in this process.

During the course of a behavioral assessment, examiners work to bring the infant through several states of consciousness to "best performance" on the various items of the NBAS scale. As we do this, we are attempting to reach out to the infants by enveloping them in an adult's caring and facilitating interaction; and we have come to realize how powerfully this functions to allow the babies to show us their processes--their organization, their mastering of the immature physiology and reflex nervous system, and the achievement of an optimal state of attention for interaction with the environment. Through this examination, we are able not only to identify motor and CNS deficits (Tronick & Brazelton, 1975) but also to produce positive responses. During the 20 minutes of administering the NBAS, we have opportunities to see the baby in nurturing situations, organizing around positive experiences; and we are thus able to visualize the infant as a whole person.

The infant assessment, when performed in the presence of parents, becomes a powerful instrument for intervention. It offers a chance to intervene in the cycle of violated expectancy which so often leads to failure in the parent-infant interaction.

In demonstrations of high-risk or damaged infants, the grieving parents are struck with and relieved by the opportunity to see their infant's positive behaviors. Since the nature of their grieving would otherwise fix them on the infant's deficits, we have found that such parents have grasped hungrily at these evidences of responsiveness. They have been able to balance their perceptions of the baby as damaged with the positive social responses which they have witnessed. In this way, the witnessed exam gives the grieving parent an opportunity to identify the assets as well as the deficits of such a baby. We have seen parents turn their grief reactions around and begin to work toward the baby's recovery.

Parents watch carefully as we work with the infants to perform the assessment. Our efforts to contain the infants, to adapt stimuli to them and to elicit responses which do not exhaust them are not overlooked. The parents observe in complete silence, ask us a few questions afterward, and often even make their own correct observations, such as, "I never knew he could see and would follow your face, but he can." "He gets exhausted if you do too much." "I see that you need to contain him so he won't get too excited." "You make your voice soft and insistent to get him to turn to you." All of these observations have come from uninstructed parents who then reproduce our techniques with their fragile babies to elicit their attention and to teach them how to maintain their own inner controls. Over time, the parents not only identify with us as we work with their child, but they begin to tell us how the baby functions best.

In the face of an expectable reaction to the baby's fragility and even in the case of identified CNS damage, parents have been able to focus on the two aspects of these high-risk babies' behavior with which they can work: 1) their need for physiological control in order to maintain homeostasis while they are producing behavioral responses, and 2) their attentional responses, which are often difficult to elicit.

The fragile infants' long latency to response, their alternating high or low threshold for receiving stimuli, and then their tendency to overshoot with an unexpectedly total response or to overload from the cost of such a response--all of these make these infants difficult to work with. When they respond, they do so with responses which often violate a parent's expectancy. In other words, their behavioral responses are so extra-normal that they set up the ingredients for a failure in their interaction, both because of the cost of responses to the infant and because of the grief reaction in the parent which is liable to be engendered by unexpectedly deviant responses. If we can understand the mechanisms behind the deviant response, the parent can begin to understand them by observing us working with their infant.

We have also come to realize that the most powerful therapy for grieving parents is to set them to work in an appropriate and sensitive way with their infant. As parents see their babies learn about their own inner organization, learn to control their overreactions; as they see the babies begin to accept and respond to their social stimuli, they can begin to find techniques for stimulation and for helping their babies toward recovery that we haven't thought of ourselves. We feel that our therapy functions best by allowing parents to see and understand the babies' observable and positive behavior, thereby accepting their negative or deviant responses. By modeling on our techniques for eliciting their "best" behavior, parents can begin to understand their infants and to see their progress. Thus, a shared demonstration of the baby's behavior and a description of the processes underlying it can become a powerful intervention in the neonatal period (Als, Tronick, & Brazelton, 1979).

We have been struck with the power of modeling our own behavior to energize and teach parents. By watching us produce the infant's "best" performance they learn to believe in the infant's capabilities and to produce this performance themselves. As they do, the internal feedback systems in the baby couple with and are reinforced by delighted responses in the parents. The two systems (internal and external) both signal and reinforce the achievement, and the child is energized to reproduce this achievement again and again. The experience of completing such a circular process might act as an organizer for the CNS; thus real recovery from deficits becomes more likely.

The infants' energy for recovery comes from two sources: 1) from within, as infants learn to achieve control and can maintain an alert state and can fuel the inner feedback cycle by completing an attentional or motor task which gives them a "sense of competence," and 2) from without, as their parents get to know them, to understand their need for containment and homeostasis, as well as their need for social and motor stimuli which are appropriately and individually geared to

their capacity to utilize them. (Of course, this kind of fueling is most appropriate to early infancy and to the early parent-infant interaction. Whether it serves a comparable purpose in older children remains to be tested.)

THE FACE-TO-FACE PARADIGM

In early infancy, the assessments have served as a window for us and for the parents into the baby's organization and ongoing development. In later infancy, a three-minute face-to-face session between mother and infant has served a similar purpose. We have found that this face-to-face paradigm produces in full-term, healthy infants up to five months of age a typical sequence of engagement, acceleration of attention by each partner, a period of reciprocal play and cyclical attention, followed by deceleration of attention (Tronick, Als, & Brazelton, 1977). This paradigm has become the target sequence for our analysis of reciprocity. Mothers who can allow for this sequence in their infants, without overloading them, are already aware of and in tune with their infant's stage of development.

The three-minute paradigm has provided important insights into the development of infants' interactive capacities. We have watched mothers and infants grow together and have identified four stages of development in the mother-infant interaction over the first four months (Brazelton & Als, 1979). The differing amounts of maternal input necessary to organize and enhance reciprocal interaction in a high-risk infant are easily identifiable in this system.

The most valuable use of the paradigm has been that of sharing it with parents. As they watch the videotaped interactional sequence between themselves and their babies, they have an opportunity to more objectively observe their own reactions and skills and to chart the development of these in their infants. They share questions and observations with us as they watch this recorded session. We have found that they use the observation as a powerful opportunity for self-evaluation as well as for noting progress in the infant. They bring to it their concerns about their babies' developmental progress and their child-rearing questions. In the case of delayed infants, mothers have identified the positive behaviors and seem to cling to them as they work to organize the baby within this social paradigm.

We are convinced that the timing of our observations, to meet the critical periods of early adjustment to the baby, have made us more useful to parents in that adjustment. Our capacity to produce the infant's "best" behavioral responses locks us to parents, as they also learn from us how to produce these responses. Within the context of such a relationship then, they can begin to model their behavior on ours. Their grief over the infant's deficits begins to turn into more productive channels, modeling on our techniques for organizing, readying and interacting with the child. In learning from the information gained in our assessments, these parents demonstrated the powerful energies that are present in caring parents for shaping their at-risk babies toward organization and eventual recovery of function.

THE ASSESSMENT AND THE EXAMINER

For a clinician, an ideal assessment would have the elements of the past, present and future which could become the base for an understanding of the infant and how he or she will interact with the environment. An assessment should be seen as an opportunity for interaction with infants and a chance to understand how each individual functions. By entering into a relationship and then reacting with them, the examiner is provided with an opportunity to understand how their parents will react to them.

In other words, any scoring of an assessment of an infant should include the subjective and clinical insights of the examiner if it is to become a base for enhancing the infant's development. For it will be through these reactions that the examiner can enter into a working relationship with both the infant and the parents to further the child's development. We have learned the power of just such an assessment in our work with the Brazelton Neonatal Behavioral Assessment Scale (BNBAS) (Brazelton, 1973).

While working to achieve "best performance" the examiners must identify with the infants in order to understand their processes of organization and social interaction more deeply. Through this identification we hope to predict fairly accurately the infants' effect on those caring adults who are also interested in helping them achieve their best performance. If we are ready to do so, we can share these observations and insights with the parents and join with them in setting goals for the child's best developmental outcome. An infant assessment is thus a multi-dimensional opportunity for diagnosis, for prediction and for entering the parent-infant interaction.

Since the BNBAS exam is a dynamic one and is clearly based on the baby's potential for organization within a nurturing interaction, the skills and sensitivity of the examiner are critical to bringing the baby to an optimal performance. (The amount of effort needed to produce organization and reactivity may be one of the most important indicators of the infant's status.) Of course, the examiner must be trained to a reliable level of awareness of neonates' potential for organization and performance, and must be comparable in performance and scoring to all other examiners, or the data collected may not be valued.

In addition, we have discovered that one exam is not as fruitful as are serial exams. Even in carefully controlled conditions, with the same neonate and with the same examiner, there are far too many impinging variables to expect high test-retest reliability. For example, a circumcision may affect a baby's performance for as much as 12 hours (Emde, Swedberg, & Suzuki, 1975). A blood test, such as a PKU or bilirubin, may well disrupt an infant for four to six hours. The neonatal period is expected to be a time of relative depletion, a time of recovery from the effects of labor and delivery and exposure to a new environment. The neonate's performance will be affected by these powerful experiences. Each set of behaviors will "recover" differently over the first few days after delivery. The more basic responses, such as autonomic or reflex-motor responses, will be less affected by external factors; they will change as a result, primarily, of maturation and time. State behaviors and interactive behaviors

(orienting to face, voice, consolability) will be influenced by experience with the environment. In a study of the cumulative test-retest correlations over the first 10 days of life, we found high correlations for those behaviors that are expected to be most stable, such as habituation and autonomous processes, and lowest correlations for behaviors that represent newly emerging and rapidly developing processes, such as state and interactive behaviors (Lester, 1980). Day-to-day, test-retest reliability was poorer in these emerging behaviors in an expectable direction.

The recognition of the importance of the effects of the caregiving environment is reinforced by the accumulating evidence from longitudinal studies which show little relationship between early infant behaviors and later developmental outcome (Sameroff & Chandler, 1975). We are treating these discontinuities as expectable results of the infant-caregiver system rather than as evidence of the infant as an isolated entity. The view of newborns as biobehavioral entities in transaction with the environment accounts for the modifications of their responsiveness over time, and it gives us a window into how they are utilizing that environment (Lester, 1979).

* SUMMARY

Our work with the neonatal assessment has helped us to better understand the normal processes of recovery from labor and delivery and the plasticity for recovery from CNS insults in the neonate. It has served as a window, for both us and the parents, into infants' organization, ongoing development and capacity to utilize the nurturant stimuli from the environment. In later infancy, the face-to-face paradigm has served the same purpose.

We have found that these observational assessments have not only revealed information about the infant's current status but have also given us the opportunity to see how these children will affect their parents and what their parents must do to organize them. Serial observations over time have furthered our understanding of neonatal development and have offered the opportunity to share with parents their baby's progress and their effect on it. This has fueled the parents' perceptions of the infants as organizable and as potentially recoverable, even after CNS insults or prematurity.

The assessment process demonstrates the infant's capacity to organize around positive experiences of interaction with a nurturing adult. This has both expanded our knowledge of neonatal development and provided parents with the chance to visualize, believe in and work with their child's positive potential. As such, it has functioned as a powerful intervention. It has proved successful beyond our expectations as a means of joining with, and helping to maximize, the energies in both infants and parents which can work toward the infant's optimal recovery.

We need more sophisticated methods for assessing neonates and for predicting their contribution to the likelihood of failure in the environment-infant interaction. We also need to be able to assess at-risk environments in order to select target populations for our efforts at early intervention. With better

techniques for assessing strengths and weaknesses in infants and the environments to which they will be exposed, we might come to understand better the mechanisms for failure in development. Understanding infants and the problems they will present may enhance our value as supportive figures for parents as they adjust to a difficult infant.

We have been working toward a more system-oriented method for presenting and scoring the Brazelton Neonatal Behavioral Assessment Scale as it is applied to at-risk infants (see chapter by Als and Duffy in this volume). Through this new method, we are coming closer to understanding organization in the fragile premature or sick infant. We are making it possible for the examiner to identify those organizational processes which are already relatively stable and those which are easily overloaded, and thus to better help parents who must work with such babies toward optimal organization and function.

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THE BEHAVIOR OF THE FETAL NEWBORN: THEORETICAL CONSIDERATIONS AND PRACTICAL SUGGESTIONS FOR THE USE OF THE APiB*

Heidelise Als & Frank H. Duffy

As educators and clinicians, we are very much aware of the individual differences between children in their interactive dynamics with the world around them. Our success in supplying the most appropriate intervention support depends on understanding and identifying the specific organizational individuality of our student or patient. The importance of identifying the individuality of each organism and recognizing this individuality over time is based on the implicit conceptualization of each organism as having a unique and intrinsic continuity which makes him or her distinct from all other organisms.

When one reviews the scientific literature over the last decade to seek support for the intrinsic continuity of development for each organism, one finds however that evidence abounds to support the opposite view. The discontinuities of early development and the unpredictability of later behavior and functioning from earlier behavior have received much attention. The disillusionment with linear prediction models that looked for simple behavioral stabilities (Lewis, 1973; McCall, 1976; McCall, Hogarty, & Hurlburt, 1972) led to the formulation of two alternative models: the transactional model (Sameroff & Chandler, 1975; Sigman & Parmelee, 1979) and the transformational model (Kagan, Kearsley, & Zelazo, 1978; Lewis, 1973; McCall, Hogarty, & Hurlburt, 1972; Piaget, 1963). The transactional model postulates that predictions which do not take into account the ongoing transactions between child and environment are bound to be weak, since early diagnosis is complicated by the responsiveness of the environment and the adaptability of the human infant. The transformational model expands upon the postulations of the transactional model by adding the formulation of the changing nature and composition of the infant's capacities with age, which accounts for the negligible correlations between infant tests and subsequent performance. Competence in infancy is said to consist of a different combination of abilities than competence at later ages. The transformational model argues for the

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existence of a symptomatic gap (Brandt, 1973; Prechtl, 1972; Saint Anne D'Argassies, 1977) that is thought to be due to the organism's inherent discontinuities of development. It is claimed that complex capacities which may reveal themselves as impaired later are not called upon earlier and, therefore, an impairment may not manifest itself until later ages. An expanded version of this is the synactive argument of continuity of discontinuity which is espoused, among others, by Emde (1978) and Brazelton (1979). This view perceives the continuity characteristic of the organism in the nature of individual discontinuity and change of behavior.

This chapter in contrast proposes a synactive theory of development for the human organism. It is presented in two distinct parts. Initially, the theory of synaction is outlined and defined with details of substantiating research from a number of investigators in different disciplines. The second part of the chapter examines how an individual organism can be assessed in concordance with the synactive formulation of development through the use of the Assessment of Preterm Infants' Behavior (APIB). By presenting the results of our own studies with the APIB and then examining the data, we propose to chart both the efficacy of the synactive concept and the tangible uses of the APIB as an assessment instrument.

SYNACTIVE THEORY OF DEVELOPMENT

The synactive model of development which we propose (Als, 1979b, in press; Als & Brazelton, 1981) identifies the degree of differentiation and modulation of behavioral organization as the main parameters of the organism's individuality and uniqueness recognizable over time. The principle of synaction subsumes the assumption of organism/environment transaction and of transformation of the organism functioning over time. The synactive model assumes that organisms, from the unicellular stage on, negotiate within themselves increasingly differentiated subsystem agenda while simultaneously eliciting from the environment that feedback which they are programmed to seek. The synactive model proposes that organisms develop in and by continuous interaction and transaction with their environment while continuously differentiating and integrating subsystems of functioning such as the autonomic system, the motor system, the state-organizational system and others. Organisms' capacities change as they develop from a blastocyst to an embryo, to a fetus, to an infant, to a preschooler, etc. Yet there exists a consistent thread to the manner in which organisms change within themselves and how they interact with the environment at each developmental stage.

Traditional tests have failed to tap this developmental consistency. In part, this is due to the difficulties inherent in identifying those parameters that can measure the individual nature of the common dynamic process of development and in finding behavioral or otherwise measurable analogs of such parameters at successive stages.

The synactive theory postulates that at every stage in development, from the unicellular stage on, the organism actively seeks to realize genetically programmed subsystem agenda which are species-specific and, within that constraint, organism-specific. At every stage, the organism actively shapes, seeks out and influences the environment and sets up a biological disposition for the re-establishment of intra- and intersubsystem balance and integration. If this balance is surpassed, due to disturbances inherent in the organism or due to environmental stresses, disintegrations can result which may lead to distortions and maladaptations. These disintegrations become established pathways in their own right, leading to canalization, narrowing and rigidity of functioning. They can also predispose the organism to reverberation in maladaptive neurological circuitry, likewise precluding the expansion of more adaptive and competence-enhancing patterns. Support for the synactive theory of development comes from various disciplines, including neurobiology, anthropology and research into the developing agenda of the human newborn.

Neurobiological Evidence for a Synactive Theory of Development

Neurobiological research demonstrates that the neurobiological ground plan is dynamically structured, complex, specifically yet flexibly programmed and that it corresponds to the incredibly complex functioning of human beings. Kuffler and Nicholls (1976), for instance, state that one of the most striking features of the nervous system is the high degree of precision with which nerve cells are connected to each other and to different tissues in the periphery, such as skeletal muscles and skin. The orderliness of the cellular connections made during development are the necessary prerequisite for all integrative mechanisms of the competently functioning organism. Recent studies (Duffy, Snodgrass, Burchfiel, & Conway, 1976; Duffy & Als, in press) have shown that subtle alterations of sensory input during development disturb performance and differentially inhibit pathways that had previously been effective. These neurobiological studies demonstrate the need for an increased understanding of the complex and dynamic ground plan according to which instructions contained in the genes are translated into organism-specific normal neurological circuitry.

Anthropologic Evidence for a Synactive Theory of Development

A second line of evidence comes from biological, physical anthropology. Anthropology has initiated serious investigations of human neurological evolution in much the same way that the field has approached the evolution and adaptability of the musculo-skeletal system and bloodgroup genetics. The access route to tracing neurological evolution, aside from inferential studies based on fossil evidence (Magoun, Darling, & Prost, 1960; Mann, 1971), is through inferences from behavioral evolution (Chomsky, 1965; Johanson & Edy, 1981; Levi-Strauss, 1969; Mann, 1971). Results of ethological techniques applied to free-ranging primates have had a major impact on the framework now used for interpreting human evolution. Several years ago, in extension of Bowlby's (1969) formulations,

we studied the behavior of newborn infants on the first contact with their primiparous mothers, focusing on facial, vocal and movement patterns such as eye opening, eye contact, visual following, fussing, tremoring, head movements and crying (Als, 1975, 1977; Katz, Rivinus-Als, & Barker, 1973; Rivinus-Als & Katz, 1971). We found that there are predictable groupings of behavior which occur with predictable frequency and are accompanied by certain behaviors of the partners more often than by others. These "fixed action patterns" qualify from an ethological viewpoint (Blurton-Jones, 1972, 1974) as releaser mechanisms as defined by Lorenz (1957).

In a study of 41 infants (Als, 1975)*, the infant's state behaviors were the most consistent determinant of maternal behavior, even in the primiparous, lower-class, young women studied (see Figure 1). The most interesting behavioral connection was that of newborn alert behaviors with maternal affection behavior. A typical sequence occurred when the mother received her sleeping baby from the nurse for the first time since delivery with the expectation to feed the infant. The mothers would first visually and tactually inspect and groom the wrapped babies, then talk to their infants, calling their name and urging them to open their eyes and wake up. If they did not comply, the mothers would unwrap them, inspect their toes, legs and genitals and then begin to circle their arms, at times pulling them to sit, picking them up and continuing to urge them now more impatiently to wake up and look at them. The infant might finally respond by building up to fussing and crying, moving agitatedly; this would be greeted with increased enthusiasm by the mother as if any specific reaction was assuring. The mothers would then try to catch the infants' attention within their crying stage. As the crying subsided and finally the eyes opened the mothers' whole display would change. The mothers would brighten, raise their eyebrows, soften their cheeks, smile and with high pitched voice animatedly greet their infants: "Hi! There you are! That's right," over and over again.

Of importance in this study (Als, 1975) were the terminating behaviors in this attentional-affective cycle. If the babies responded with increasing brightness (e.g., raising their eyebrows and softening their cheeks, widening their eyes and shaping their mouth into an "ooh,"), the mothers might pull them close and nuzzle and kiss them, thus resetting the attentional intensity cycle. If the mothers continued drawing the infants out and expanding on their alertness and attention more and more, pressing them with an alluring voice and animated face, the babies might break the intensity by averting their eyes momentarily or by a sneeze or a yawn, or, in the less well-regulated baby, by going to fussing or motoric arousal, thus resetting the attentional cycle on their part.

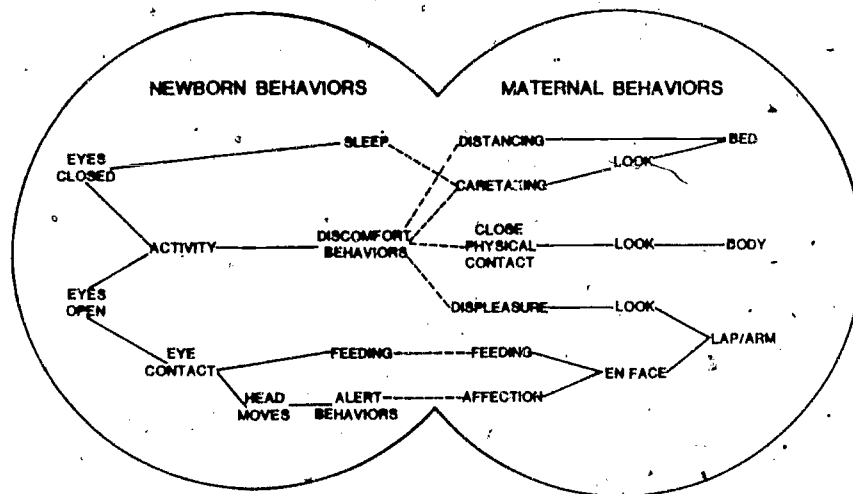
The study identifies an interactive cycle of responses and suggests that, from birth, both mother and infant are programmed to bring about mutual acknowledgment and refueling. These apparently innate behaviors take on great importance when viewed from the perspective of the evolution of the human race. The speciation of the hominids from a common ancestral primate may be seen in terms of the hominids' ability to create a material culture which is essential for their survival (Holloway, 1969, Vygotsky, 1978). Material culture as

*In this study the state behaviors observed were: whether the infants had their eyes closed and were either quiet motorically or vocally and therefore presumably sleeping; or were moving and fussing and therefore presumably uncomfortable; or whether their eyes were open and they were feeding; or the eyes were open, and they showed eye contact with or without visual following to the mother's face.

an adaptive mechanism presupposes greater emotional and social cooperativeness, greater flexibility of communication, and a higher degree of cognitive development and learning--which in turn is based on more social interaction than is necessary for any other primate species. The identification of effective social behaviors in human newborns would tend to both support and be supported by such an evolutionary view.

Figure 1

Human Newborn and Maternal Behaviors and their Interactive Fit



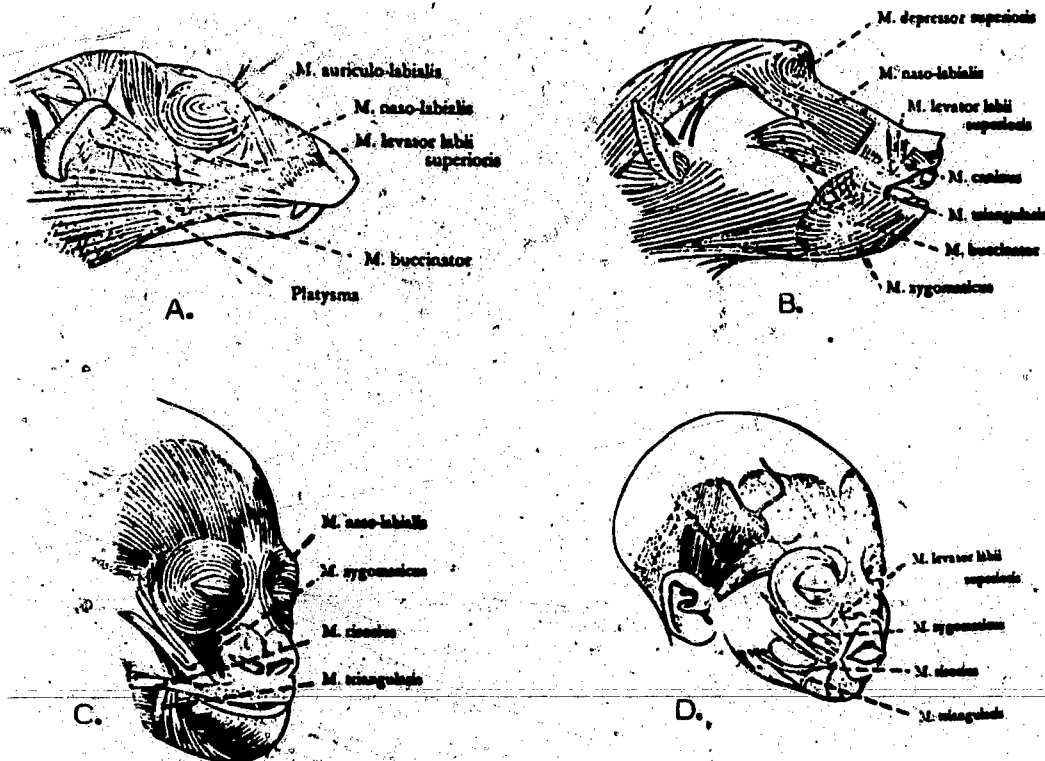
Note. Reprinted with permission from Als, H. The human newborn and his mother: An ethnological study of their interaction. Unpublished doctoral dissertation, University of Pennsylvania, 1975.

Comparative studies of facial displays in other primates offer important data strengthening the hypothesis that neonatal state behaviors, especially facial behaviors, have evolutionary significance. Buettner-Janusch (1966) observed throughout the order Primate a correlation between the degree of complexity of social group structure and the degree of facial flexibility. Bolwig (1959a, b, 1964) and Andrew (1963a, b), following earlier work by Huber (1931), also stress the enormous change in facial morphology and behavior observable when comparing the solitary, largely nocturnal prosimians (Figure 2a), to the increasingly flexibly social diurnal monkeys (Figure 2b), apes (Figure 2c) and humans (Figure 2d). Aside from the decreasing importance of the overriding platysma and the increasing differentiation of musculature around the eyes and in the lower face, culminating in the appearance of the triangularis muscle and its differentiation--yielding the risorius or laughing muscle--there are some morphological features in humans that go beyond the facial communication repertoire even of the great apes. These

include the everted red lips emphasizing the line of the mouth, the large area of the eyeball visible around the pigmented iris, and the increased muscular independence of the periocular from the perioral muscle groups.

Figure 2

Facial Muscles of the Primates
A. Lemur; B. Catarrhine Monkey, Papio; C. Gorilla; D. Human Child



Note. Reprinted by permission from Bolwig, N. Facial expression in primates with remarks on a parallel development in certain carnivores. *Behavior*, 1964, 23, 167-193.

Anthropological evidence thus supports the theory that from birth on, human newborns are structured to elicit actively the emotional and affective/cognitive support and input which launches and fuels their own increasing behavioral differentiation and organization (Als, 1977). Human neonates are active shapers of their own development, and a high value appears to be placed by themselves and by the caregiving environment on their interactive attentional capacity, much

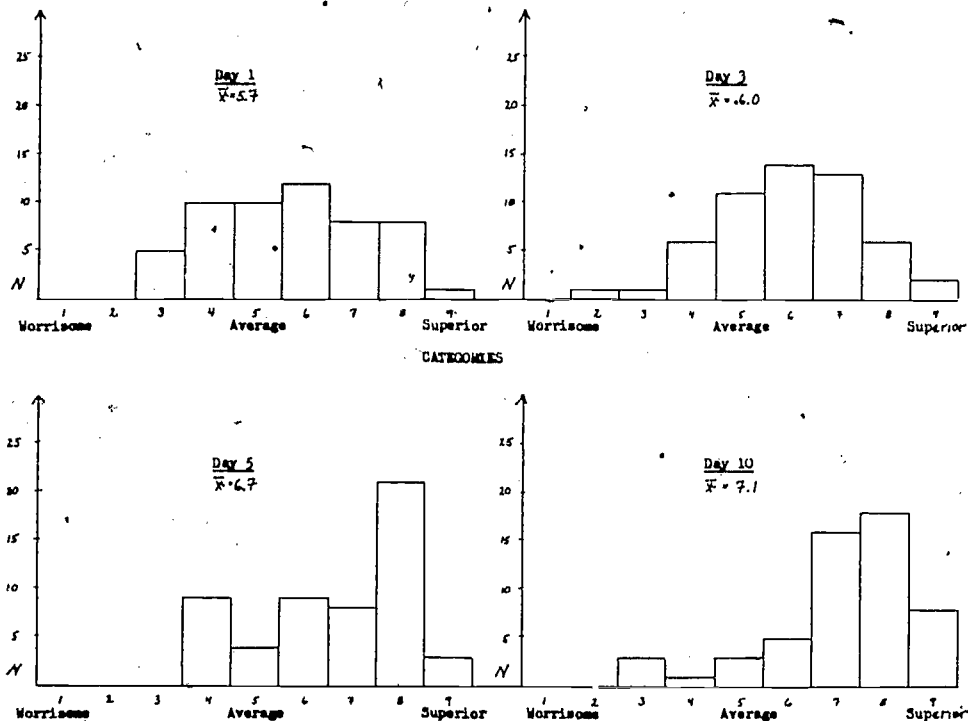
in keeping with their specific humanness. The synactive theory identifies the increased freeing up of the alert state--which implies social, emotional and cognitive availability and flexibility--as the key developmental agendum of the healthy full-term newborn.

Alertness: the Developmental Agendum of the Human Newborn

Support for the synactive postulation that the increasing ability to be alert is the newly emerging developmental agendum of the human newborn comes from a study of 54 full-term healthy newborns (Tronick, Wise, Als, Adamson, Scanlon, & Brazelton, 1977) who were examined repeatedly in the course of the first 10 days of postnatal life with the Brazelton Neonatal Behavioral Assessment Scale (BNBAS) (Brazelton, 1973). Data displayed in Figure 3.

Figure 3

Distribution of Profile Categories of
Healthy Full-term Newborns Over the First 10 Days of Life
(N = 54)



Note. Reprinted by permission of John Wiley & Sons, Inc. From Brazelton, T.B., Als, H., Tronick, E., & Lester, B.M. Specific neonatal measures: the Brazelton neonatal behavior assessment scale. In J. Osofsky (Ed.), Handbook of infant development, 1979.

Using the data reduction scheme of four a priori dimensions as developed by Adamson, Als, Tronick and Brazelton in 1975, (Als, Tronick, Lester, & Brazelton, 1977), it appears that on overall behavioral organization there is a normal distribution on day one, which shifts to the right--that is, increasingly improved performance--by day 10 (Figure 3) (Brazelton, Als, Tronick, Lester, 1979).

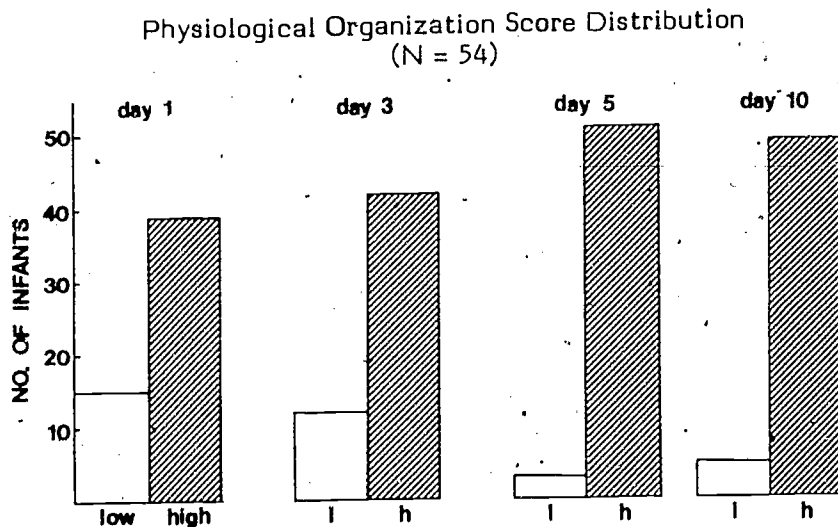
These a priori dimensions group the BNBAS data into four behaviorally observable, conceptually defined dimensions of functioning:

1. The physiological dimension as behaviorally exemplified by tremulousness, startles and skin color changes.
2. The motor dimension as behaviorally exemplified by tonus, motor maturity, level-specific complex motor activities (i.e., pull-to-sit capacity, hand-to-mouth ability, defensive reactions) and a series of elicited reflexes.
3. The state regulation dimension as behaviorally exemplified by predominant states, lability of states, peak of excitement, rapidity of build-up, irritability and self-quieting.
4. The attentional/interactive dimension as behaviorally exemplified by overall alertness, ability to attend to inanimate and animate stimuli presented, cuddliness and consolability.

Examining these dimensions or subsystems of functioning separately, the following becomes apparent (Als, 1978):

As Figure 4 shows, the physiological system is already quite stable in these healthy babies on day one and continues to be so through day 10.

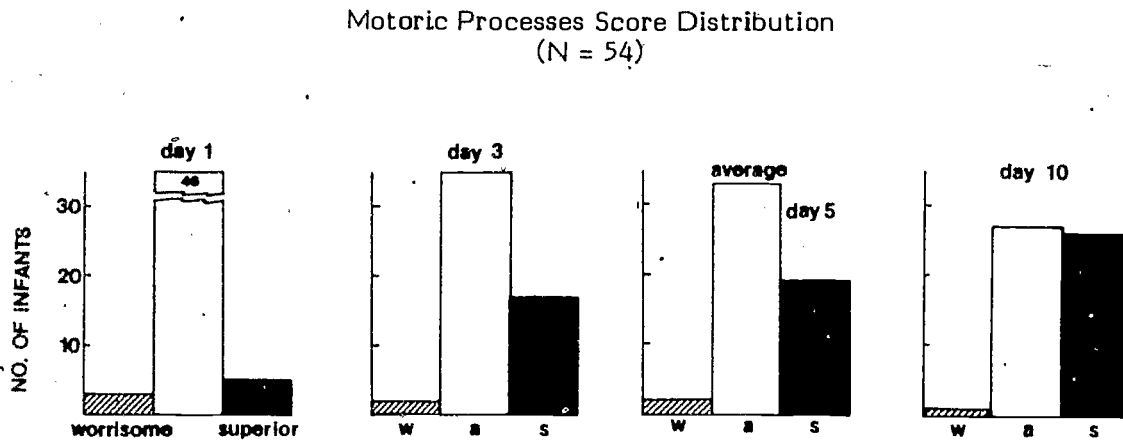
Figure 4



Note. Reprinted by permission of the Society for Research in Child Development from Als, H. Assessing an assessment. In A. Sameroff (Ed.), *Organization and stability of newborn behavior: A commentary on the Brazelton neonatal behavioral assessment scale*, (Monograph of the Society for Research in Child Development), 1978, 43, 14-29.

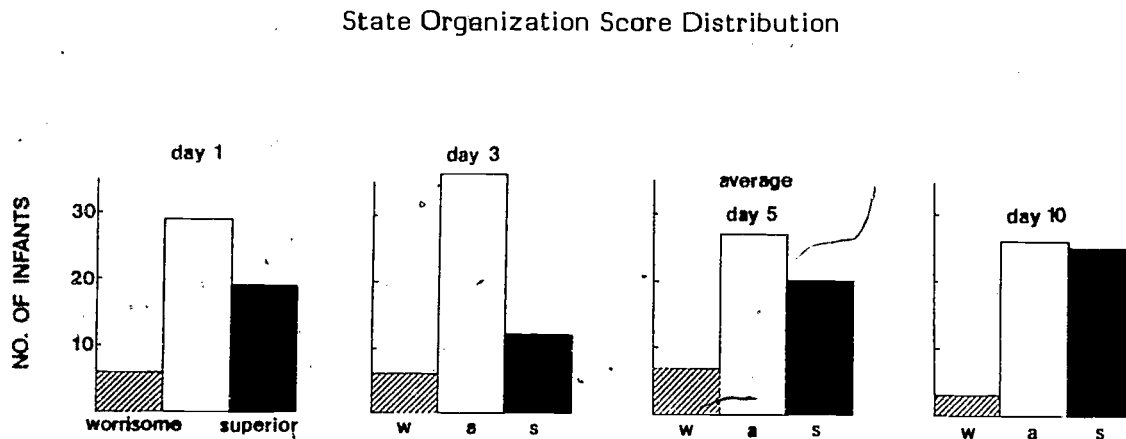
The motor system, as Figure 5 indicates, shows some room for improvement from day one to day 10, mainly between the middle and the optimal category.

Figure 5*



The state system shows a similar shift from day one to day 10 as can be seen in Figure 6.

Figure 6*

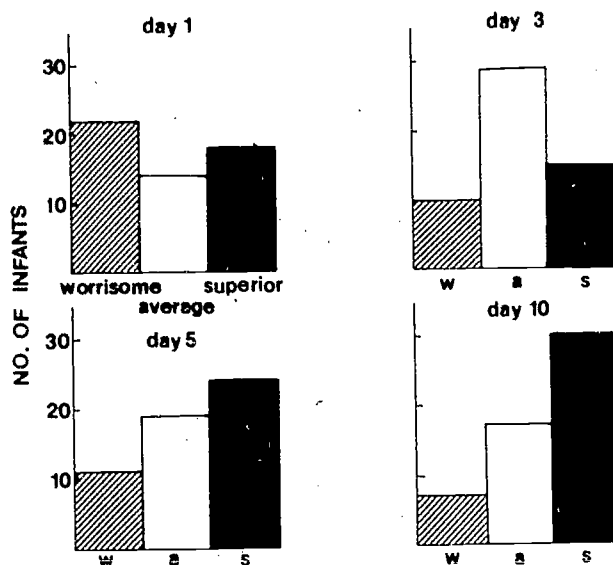


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The attentional interactive system, as Figure 7 shows, reflects the most dramatic shift from day one to day 10.

Figure 7

Interactive Organization Score Distribution



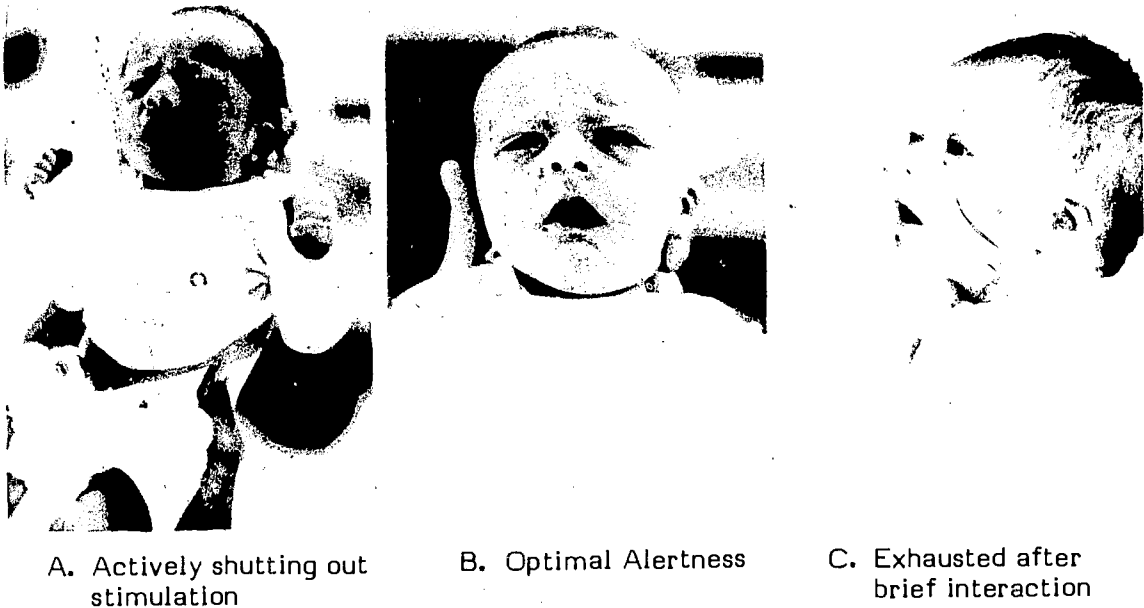
Note. Reprinted by permission of the Society for Research in Child Development from Als, H. Assessing an assessment. In A. Sameroff (Ed.), *Organization and stability of newborn behavior: A commentary on the Brazelton neonatal behavioral assessment scale* (Monograph of the Society for Research in Child Development), 1978, 43, 14-29.

The most room for change is in the interactive process, i.e., the differentiation of the alert state, the newly emerging agendum of the full-term infant. How sparse and taxing this differentiation can be in the less well-organized newborn is seen in Figure 8, derived from a study of underweight, normally tall, full-term infants (Als, Tronick, Adamson, & Brazelton, 1976).

These infants typically protect themselves against freeing-up of alertness and having to attend to stimulation around them--as their high-guard arm position, clenched fists and drawn mouth show. When they allow themselves to rouse to some degree of alertness, they appear pained, glassy-eyed and frowning. Their earlier increased flexor tonus gives way to limp flaccidity; their color pales, especially around nose and mouth. Although they may eventually muster a coordinated visual-following response, they continue to appear overtaxed. When the very brief interaction episode is terminated, they are now exhaustedly awake and unable to return to a sleep state easily.

Figure 8

Example of Behavioral Organization of Full-Term Infant
With Low Ponderal Index



Note. Reproduced by permission from Als, H., Tronick, E., Adamson, & Brazelton, T.B. The behavior of the full-term but underweight newborn infant. Developmental Medicine and Child Neurology, 1976, 18, 590-602.

These studies (Als, Tronick, Adamson, & Brazelton, 1976) describe the continuous interplay of five behaviorally observable subsystems of the organism's functioning: the autonomic system, the motor system, the state system, the attentional-interactive system and the self-regulatory ability. The organism attempts to stay in a state of balance and relaxed integration on the basis of which the organism then pushes to attain the expansion and differentiation of the next newly emerging agendum. The organism's individuality lies in the degree of flexibility and differentiation and the degree of modulation with which the organism is able to build up to the next step and return to a balanced, integrated state. The organism sets up numerous and complex feedback loops within itself and in interaction with the environment, realizing its own competence and making this competence more differentially available to its developmental progression.

Synaction: A Biphasic Model of Development

The developmental progression of the infant as seen in the synactive model is carried by a continuous balancing process, e.g., of reaching out and going towards, incorporating and processing more, and then defending against, shutting off, avoiding and withdrawing. When environmental input is too demanding, as we saw in the study of the thin newborns, (Als, et al., 1976) (Figure 8) protective defenses are called up. When the input is just right in its timing and intensity, the organism reaches toward it, seeks it, may even provoke or elicit it; then actualizes the newly emerging program thus activating pathways which will be more easily activated the second or third time they are used. The synaptic competences thus activated will have spin-offs beyond their own activation, sensitizing neighboring dormant circuits and lowering their threshold for circuit firing when the appropriate stimulus is met, thus increasing the band of modulated functioning (Als & Brazelton, 1981).

The concept of this dual antagonism and integration of defense and approach has been articulated by researchers in other contexts. Schneirla and Rosenblatt (Rosenblatt, 1976; Schneirla, 1959, 1965; Schneirla & Rosenblatt, 1961, 1963) have discussed the observable passing of a threshold from approach to avoidance as operative in the process of the gradual specialization of central arousal processes. This leads to functionally adaptive action patterns, such as suckling, nipple grasping, huddling and so on, in altricial mammals. A similar formulation underlies the orientation literature led by Sokolov's (1960, 1963) work on the orienting reflex, the recent integration by Haith (1980) of rules of visual functioning in the human infant, and the work of Stechler and his associates (Stechler & Carpenter, 1967; Stechler & Latz, 1966). Stechler's research spells out the concepts of active attentional-perceptual reaching out by the organism and the selective processing and incorporating of aspects of its environment as bases of affective development. Orlebeke and Feij (1979) see these traits as personality correlates, reflecting the relative strength of the neurophysiological substratum, basing their formulation on the work of such researchers as Rozhdestvenskaya (1964) and Nebylitsyn (1960, 1966).

Support for the more general applicability of the biphasic model of development comes from the neurophysiological study of the motor system. According to Denny-Brown (1966, 1972), the organism always strives for smoothness of integration. Underlying this striving is the tension between two basic antagonists of behavior (two basic physiological types of response) as seen in movement disorders such as athetosis: the exploratory and the avoiding; the towards and the away; approaching, or reaching out, and withdrawing, or defending. The two responses are at times released together and in conflict with one another. If a threshold of organization-appropriate stimulation is surpassed, one may abruptly switch into the other.

How basic these two poles of motor behavior are to the organism's functioning can be inferred from the experiments by Duffy and Burchfiel (1971, 1980) who investigated the nature of the inputs to single cells in the somato-sensory cortex (cortical area 5) of the rhesus monkey that provide feedback information to the motor system (area 6). These cells are apparently sensitive to specific tactile and kinesthetic stimuli and are optimally activated by the complex approach and avoidance movements described by Denny-Brown (1966, 1972). It is of interest that as the somato-sensory cortex filters the massive amounts of sensory information that impinge upon it for transmission to the motor system, it distills and simplifies this information along the towards-away (flexion-extension) axis. The work of Twitchell (1963, 1965; Twitchell & Ehrenreich, 1962) has shown the applicability of this dual antagonist integration theory to the study of the grasp and of reaching behavior in the human infant.

The synactive model draws from these various lines of evidence and utilizes the principle of dual antagonist integration. This principle has been productive in investigating the behavioral patterns of the very young infant in order to assess the level of threshold from integration to stress along the various subsystems of the organism. For instance, a newborn is drawn to the animated face of the interacting caregiver. As the infant's attention intensifies, the eyes widen, eyebrows raise and mouth shapes toward the interactor (Als, 1975, 1977). The response, which gradually is confined to the face, will early on involve the total body in an undifferentiated way (Figure 9a) (Als, Lester, & Brazelton, 1979). If the dampening mechanisms of this intensity are not established, as in the immature or dysmature organism, the whole head may move forward, arms and legs may thrust toward the interactor, and fingers and toes will extend toward that person. The return to the baseline may be initiated by the organism through such homeostatic behavioral regulators as eye averting, yawning, sneezing, or hiccoughing (Figure 9b), or it may be initiated by the caregiver through kissing, nuzzling, or moving the infant closer, thus resetting the cycle as mentioned earlier. If neither of these regulation mechanisms are brought into play, or if the initial input is too strong, the organism may turn away, grimace, extend the arms, arch the trunk, splay the fingers and toes, change color, show irregular respiration, spit up and/or have a bowel movement. In short, the infant will show active avoidance behaviors on the motor system and autonomic system levels of functioning. If these mechanisms are functioning well, the organism will reestablish a level of modulation (Figure 9c) via, for instance, motoric flexion and self-maintenance. The task, for the assessor or researcher is the identification of synchronous and cohesive functioning, thresholds of disruption, and openings of relative coherence which may be necessary in order for a shift to new differentiation to occur.

Figure 9

Preterm Infant, 34 Weeks PCA



A. Heightened alertness with motoric overflow



B. Yawning as resetting of alertness



C. Alertness with active motoric self-maintenance

Note. Reprinted by permission from Figures 8 and 9, page 186 in *Infants Born at Risk* by Tiffany M. Field, Anita M. Sostek, Susan Goldberg and H.H. Shuman (Eds.). Copyright 1979, Spectrum Publications, Inc. New York City.

The synactive model of subsystem differentiation in the organism thus is characterized by the principle of Synaction--the simultaneity of all subsystems in negotiation with one another and with the environment from conception on. The process of development appears to be one of stabilization and integration of some subsystems, which allows the differentiation and emergence of others which then, in turn, feed back into the integrated system. In this process, the whole system is reopened and transformed to a new level of more differentiated integration from which the next newly emerging subsystem can further differentiate and press to actualization and realization (Als, 1979b, in press). The emerging band of modulation in its flexibility and width becomes the index of an organism's individuality. To paraphrase Erikson (1962), self-actualization is participation with the world and interaction with another with a minimum of defensive maneuvers and a maximum of activation, a minimum of idiosyncratic distortion and a maximum of joint validation.

ASSESSMENT OF THE INDIVIDUAL ORGANISM

The questions of whether life is a sequence of opportunities to thrive on or a sequence of costly onslaughts to be coped with are crucial ones in the development of an assessment instrument. An effective assessment must incorporate considerations of integrative level--width of modulation band, threshold to defense and of cost. In response to these considerations we have constructed a systematic behavioral assessment procedure for the preterm infant, referred to as the Assessment of Preterm Infants' Behavior (APIB) (Als, in press; Als & Brazelton, 1981; Als, Lester, Tronick, & Brazelton, in press-a, in press- b).

Prior to describing the APIB instrument, its relationship to the BNBAS and our studies with it, we will examine the behavioral organization of the preterm infant. The synactive conception of preterm infants' behavioral organization is a specific example of the larger synactive theory developed in the first part of this chapter.

Behavioral Organization of the Preterm Infant

Assessment of an individual preterm infant's functioning in the context of a synactive model requires identifying the infant's standing on the matrix of subsystem development in interplay with the environment. The principle of species-specific adaptation makes it clear that the surviving human preterm infant is a product of modern medicine, i.e., cultural evolution. The earlier the fetus is delivered, the more dramatic is the shock period which the organism enters. During this period of shock, the organism's subsystem functioning temporarily lapses and the organism attempts to ascertain how best to integrate the new environment's demands with its differentially triggered subsystems.

The natural developmental agenda of the organism includes gradual control over responses elicited by external stimuli. The developing fetus undergoes a genetically preprogrammed motor-system development, modulated by interaction with environmental influences that penetrate the multi-layered, protective stimulus barriers of the maternal organism, placenta and amniotic sac (Freud, 1920). At parturition, full-term newborns have reached a level of organization where they can cope with the onslaught of the complex and demanding stimuli that bombard them. Full-term newborns utilize these stimuli as developmental incentives. However, children who are born prematurely may be unprepared to integrate extrauterine environmental stimuli easily into their current developmental agenda. In contrast to full-term infants, preterm neonates expend considerable energy defending themselves from the bombardment of inappropriately patterned and developmentally depletive stimuli. We know that environmental influences may trigger "critical periods" of sensory neural development (e.g., Mower, Berry, Burchfiel, & Duffy, 1981; Duffy & Als, in press). It may be that such critical periods are prematurely initiated at the time

of premature parturition. Since preterm infants find themselves unprepared to integrate environmental influence, they are, in a sense, sensory-deprived as a result of their protective "shutting out" of the stimuli. Thus the preterm infant develops under two handicaps: 1) self-induced sensory deprivation, and 2) an overemphasis and over-reliance upon "shutting out" as a mode of handling new demands. It is important that throughout the first year of life, many prematurely born infants have a more restrictive range in various expressive modalities (e.g., facial expression and vocalization), and less flexible fine and gross-motor performance (Als & Duffy, in preparation). Correspondingly, at later ages, premature infants are over-represented in the behavior problem and learning-disabled populations (Drillien, Thomson, & Bargoyne, 1980; Saint-Anne d'Argassies, 1977).

Just how distorted and potentially stressful the environment is for the extrauterine fetus is apparent when we focus on the normal development of the intrauterine fetus. Recent studies, such as those of Milani-Comparetti (1980), Birnholz (1980), Birnholz, Stephens and Faria, (1978), and of Fox (Fox, Inglis, & Steinbrecher, 1979), using ultrasonography, and the earlier photographic studies using fiber optic techniques, conducted by Nilsson (1973), indicate how complex and competent the embryonic and fetal organism is. The intrauterine organism has adapted to an environment of regulated temperature; continuous cutaneous input from the surrounding amniotic fluid; and the comparatively plastic, yet finitely and contingently reactive intrauterine enclosure. During this period sensory inputs are relatively muted by the maternal state and chemical cycles, and support for physiological needs such as alimentation and digestion are provided. In this environment the fetus engages in increasingly complex and differentiated coordination of breathing movements, eye movements and other movement patterns. The fetus also maintains a comparatively flexed modulated base posture with head, shoulder, trunk, arm and leg flexion from which it modifies movements to specific extensions of legs and arms, engaging in alternating jumps and reflexions. The locomotor patterns of the fetus may well indicate active participation in its own intrauterine development. Milani-Comparetti (1980), for instance, sees the intrauterine stepping movements with alternating neck and head extensions as active fetus-initiated propulsions seeking the "invitation of softness" for the head to become engaged in the pelvic opening for normal vertex delivery.

Prior to the advent of ultrasonography, Humphrey (1968a, b) espoused similar observations of active fetus participation in development on the basis of in vitro studies when she traced palatal shelf elevation as interactive with fetal sucking patterns. These considerations can help us understand the grappling of the prematurely extra-uterine fetus who is trying to maintain the previously well-differentiated functioning patterns. The fetus attempts to integrate the differential discrepancies of subsystem readinesses in the face of negotiating an inherently non-adaptive environment, on which he or she is nevertheless critically dependent for survival.

After a period of "shut down" or "holding", infants reactivate themselves and attempt to get on with their development as best they can. Our task is to identify with the infant's support systems and isolate the situations in which these infants are able to bring about smooth and balanced functioning which is critical for their realization of new developmental pathways. Freeing up the small strands of the next developmental agenda sets and maintains the path of development in a positive direction and avoids the unwitting reinforcement of only the disturbing, distorted defensive behaviors. All too readily, a discrepant organism-environment interaction can lead to a vicious cycle of reverberating distortion and disorganization (Herzog, 1979), with possible neurosynaptic complications. It is not surprising, from a synactive conception of development, that the number of latently autistic children and children with organizational, impulsivity and attentional deficits (OIAD) includes a disproportionately high number of prematurely born infants (Denckla, 1978).

Description of the APIB

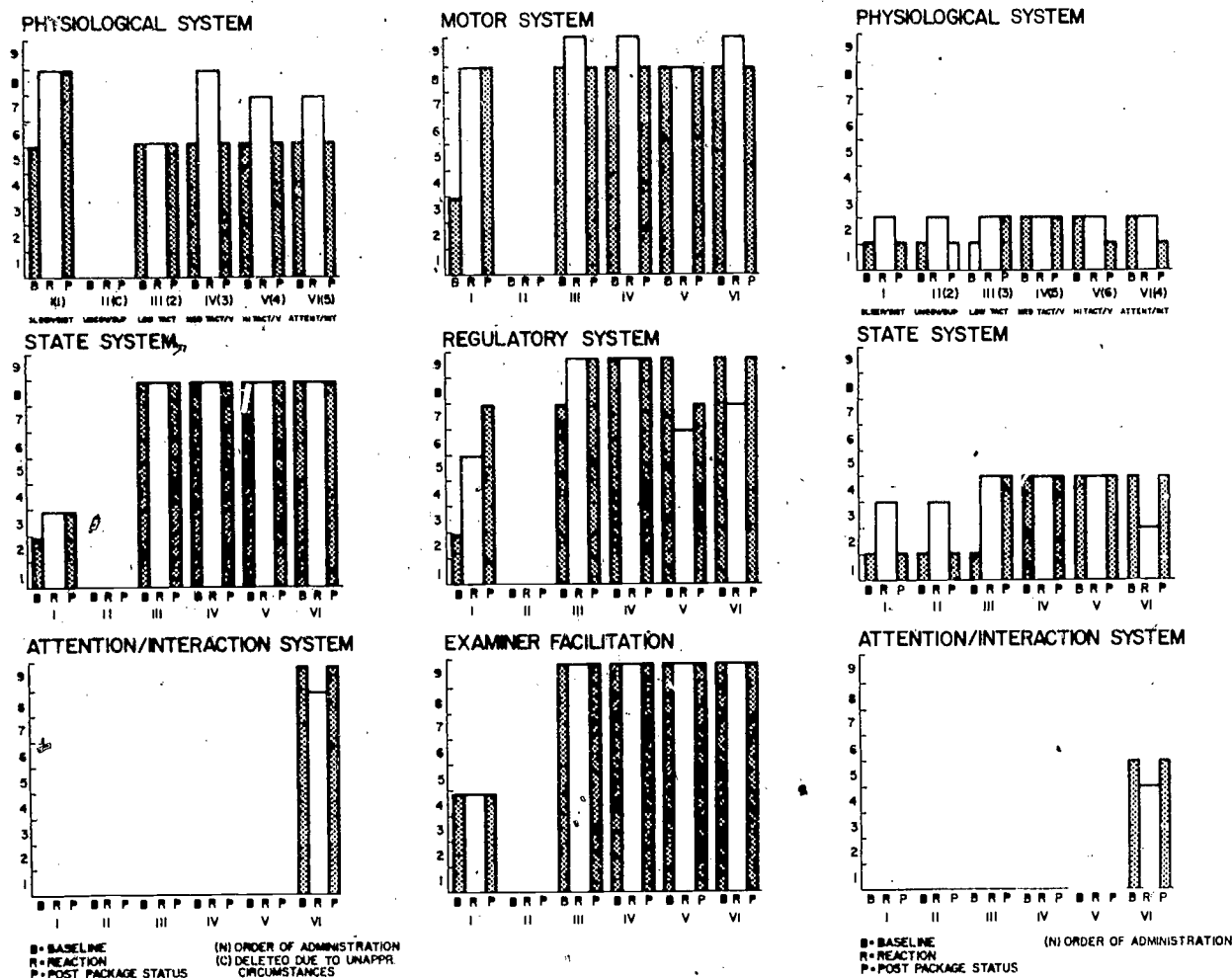
Our task over the last years has been to develop a systematic assessment for the current status of modulation and differentiation of a very young infant. We have based this work on the BNBAS (Brazelton 1973) which we expanded and partially reconceptualized--yielding the APIB. In the Assessment of Premature Infants' Behavior (APIB), the maneuvers of the Brazelton Neonatal Behavioral Assessment Scale (BNBAS) (Brazelton, 1973) are seen as graded sequences of increasingly demanding environmental inputs or packages. The packages move from distal stimulation (Package #1 of the BNBAS) presented during sleep, to mild tactile stimulation, to medium tactile stimulation paired with vestibular stimulation, to more massive tactile stimulation paired with vestibular stimulation. The Attentional/Interactive Package (#5) is administered whenever, in the course of the examination, the infant's behavioral organization indicates availability for this sequence. It receives high priority in the examiner's attempts to facilitate the infant's organization (Als, 1978).

During each increasingly demanding package we monitor the infant's reactions and behaviors along five systems of functioning: the autonomic physiological system, the motor organizational system, the state organizational system, the attentional/interactive system, and the self-regulation system. We also monitor the kind of graded examiner facilitation that is necessary to bring the infant to optimal performance and/or to help the infant return to an integrated, balanced state. These system parameters are scaled from 9 (disorganized performance) to 1 (well-organized performance) and can also be graphed on a summary grid, visually presenting the width of the modulation band, above the graphed scores. Figure 10a shows the performance of a poorly differentiated infant at term equivalent who is still hypersensitive and needs

Figure 10

Behavioral Organization of Two Infants At Equivalent Term Age: APiB Systems Graph

The Behavior of the Fetal Newborn

BEHAVIORAL ORGANIZATION: PT AGE 39.6 WEEKS
(A.PiB)BEHAVIORAL ORGANIZATION: FT AGE 40.3 WEEKS
(A.PiB)

A. Poorly Differentiated Infant

B. More Well Differentiated Infant

Note. Reprinted by permission of the American Academy of Child Psychiatry. From Als, H., & Brazelton, T.B. A new model of assessing the behavioral organization in preterm and full-term infants: Two case studies. *Journal of the American Academy of Child Psychiatry*, 1981, 20, 239-263.

considerable facilitation from the environment. The band of modulation, graphed as the space above the scores of relative organization, is very narrow. Figure 10b, in contrast, shows the performance of a well-differentiated infant of comparable post-conceptual age, whose graph depicts a wide band of flexibility and modulation (Als & Brazelton, 1981). Figure 11 shows Scoresheet I, the Systems Sheet, of the APiB.

Figure 11

Systems Scoresheet of the APiB

ASSESSMENT OF PRETERM INFANT BEHAVIOR (APiB) H. Als, Ph.D. © February 1979
T.B. Brazelton, M.D.

INFANT'S NAME: _____ MED. REC. NO.: _____ DATE OF BIRTH: _____ AGE (Post-conception): _____

TIME OF LAST FEEDING: _____ TYPE OF FEEDING: _____ CURRENT INTERVAL BETWEEN FEEDS: _____

INITIAL CIRCUMSTANCES OF INFANT: POSITION: ☐ SUPINE ☐ PRONE ☐ SIDE ☐ HEAD: ☐ RIGHT ☐ LEFT ☐ MIDLINE ☐ COVERING: ☐ DIAPER ☐ SHIRT ☐ CLOTHES ☐ BLANKET(S)

INFANT'S INITIAL STATE: _____ INFANT'S PREDOMINANT STATE: _____

WEIGHT: _____ LBS. _____ OZS. _____ HEIGHT: _____ INCHES _____ HEAD CIRCUMFERENCE: _____ INCHES _____ PONDICAL INDEX: _____

DATE OF EXAM: _____ TIME OF EXAM: _____ PLACE OF EXAM: _____ PERSONS PRESENT: ☐ MOTHER ☐ FATHER ☐ SIBLING(S) ☐ OTHER: _____

INTERFERING VARIABLES: _____ EXAMINER: _____ VIDEO: _____ DURATION OF EXAM: _____

SCORE SHEET I - SYSTEMS LEGEND: B = Baseline R = Reaction P = Post-package Status

ORDER OF PKG.	PHYSIOLOGY			MOTOR			STATE			ATTN/INTERACT			REGULATORY			EXAM FACIL.		
	B	R	P	B	R	P	B	R	P	B	R	P	B	R	P	B	R	P
PACKAGE I SLEEP/DISTAL																		
PACKAGE II UNCOVER/SUPINE																		
PACKAGE III LOW TACTILE																		
PACKAGE IV MEDIUM TACTILE/VESTIBULAR																		
PACKAGE V HIGH TACTILE/VESTIBULAR																		
PACKAGE VI ATTENTION/INTERACTION																		

COMMENTS:

Figure 12 Behavioral Items: Scoresheet II of the APIB

SCORE SHEET II - PACKAGES AND MANEUVERS										ORDER
I: SLEEP/DISTAL	Decrement	BNBAS	Ease of Elicitation	Timing	Recycling	Dis-organization	Discharge			
LIGHT	Decrement	BNBAS	Ease of Elicitation	Timing	Recycling	Dis-organization	Discharge			
RATTLE	Decrement	BNBAS	Ease of Elicitation	Timing	Recycling	Dis-organization	Discharge			
BELL	Decrement	BNBAS	Ease of Elicitation	Timing	Recycling	Dis-organization	Discharge			
II: SLEEP PRONE/SUPINE UNCOVER	Capacity to deal with									
PRONE TO SUPINE	Capacity to deal with									
III: LOW TACTILE	Capacity to deal with									
FREE FEET/HANDS	BNBAS	Ease of Elicitation	Timing	Recycling	Dis-organization	Discharge				
HEEL TOUCH	BNBAS/R	BNBAS/L								
PLANTAR GRASP	BNBAS/R	BNBAS/L								
FOOT SOLE STROKE (Babinski)	BNBAS/R	BNBAS/L								
CLONUS	BNBAS/R	BNBAS/L								
PALMAR GRASP	BNBAS/R	BNBAS/L								
PALMAR MENTAL GRASP	APIB									
PASSIVE MOVEMENT ARMS	Resistance R	Resistance L	Recall R	Recall L	BNBAS/R	BNBAS/L				
PASSIVE MOVEMENT LEGS	Resistance R	Resistance L	Recall R	Recall L	BNBAS/R	BNBAS/L				
ARM/LEG DIFFERENTIATION	APIB									
GLABELLA	BNBAS									
ROOTING	BNBAS/R	BNBAS/L								
SUCKING	BNBAS									

SCORE SHEET II - PACKAGES AND MANEUVERS (Continued)										ORDER
IV: MEDIUM TACTILE/VESTIBULAR	Capacity to Deal With									
UNDRESS	BNBAS	Hyper-extension	Hyper-flexion							
PULL TO SIT	BNBAS									
STANDING	Umbrella	BNBAS								
WALKING	Umbrella	BNBAS								
PLACING	Umbrella R	Umbrella L	BNBAS/R	BNBAS/L						
INCURVATION	BNBAS/R	BNBAS/L								
CRAWL	APIB	BNBAS								
CUDDLING	Vertical	Fetal Tuck	Horizontal	Fetal Tuck	BNBAS					
TONIC NECK REFLEX	BNBAS/R	BNBAS/L								
DEFENSIVE REACTION	BNBAS									
V: HIGH TACTILE/VESTIBULAR ROTATION	Head R	Head L	Eyes R	Eyes L	BNBAS/R	BNBAS/L	Nystagmus			
MORO	Arms Extension	Arms Adduction	Legs	BNBAS						
VI: ATTENTION/INTERACTION	Elicitation Maintenance	Orientation (B)	Orientation (A)	Effort	Cost	Quality				
ANIMATE VISUAL & AUDITORY (Face & Voice)	Elicitation Maintenance	Orientation (B)	Orientation (A)	Effort	Cost	Quality				
ANIMATE VISUAL (Face)	Elicitation Maintenance	Orientation (B)	Orientation (A)	Effort	Cost	Quality				
ANIMATE AUDITORY (Voice)	Elicitation Maintenance	Orientation (B)	Orientation (A)	Effort	Cost	Quality				
INANIMATE VISUAL & AUDITORY (Rattle)	Elicitation Maintenance	Orientation (B)	Orientation (A)	Effort	Cost	Quality				
INANIMATE VISUAL (Ball or Rattle)	Elicitation Maintenance	Orientation (B)	Orientation (A)	Effort	Cost	Quality				
INANIMATE AUDITORY (Rattle)	Elicitation Maintenance	Orientation (B)	Orientation (A)	Effort	Cost	Quality				

The use of the APIB in this graded fashion with a consistent focus on the five subsystems allows us to identify the threshold of integration and stable organization of the infant and the areas of current poor functioning and regulation, as well as the areas of beginning modulation and differentiation.

Aside from the subsystem organization descriptors, the APIB allows documentation of discrete behavioral dimensions as captured in the full-term BNBAS with a range of behaviors appropriate for the preterm infant (Figures 12 and 13.) The manual and score sheet of the APIB are organized so that the full-term BNBAS scores are distinctly identified in the APIB scoring system and are easily read off where appropriate. This makes the APIB useful for comparative work with previously collected BNBAS data on full-term subgroups. The scores from Sheets II and III can be examined as individual items or grouped into dimensions or clusters, as has been done successfully with the 26 BNBAS behavioral items (Als, Tronick, Lester, & Brazelton, 1977; Sostek & Anders, 1977). As we shall discuss later Score Sheet III documents summary behavioral parameters.

Of particular interest within the synactive formulation is the catalog of specific regulation behaviors (Figure 13), which we have grouped into defensive and groping behaviors. These behaviors are organized from those involving autonomic visceral control (spit-ups, gags, hiccoughs and bowel movements) to those involving global motor control (arching, arm and leg extensions as in airplaning, salutes and sitting on air, finger splays, and grimacing) to those involving more subtly differentiated regulators (eye averting, sneezing, yawning and sighing). On the groping and approach dimension, we distinguish, among others, tongue extensions, hand-on-face behavior, body tucking, grasping, suck search, hand clasping, foot bracing, and more subtly differentiated behaviors such as visual locking, cooing and ooh-face configurations. Attention to and articulation of these behaviors reveal how close the infant is to being overloaded or how severe is the level of overstimulation versus the investment in accomplishing a particular postural or attentional goal. This grouping of behaviors has been very helpful in aiding parents and nursery personnel to modify their babies' environments and allowing the infant increasingly autonomous control and self-regulation while expanding their band of modulated functioning.

The APIB examination is appropriate for infants who can maintain themselves in an open isolette or crib, in room temperature and room air. This is usually the stage when parents become more actively involved in caregiving with the infant and is therefore well suited to capturing their energies for the infant via the examination. This timepoint may vary from as early as 30 to 32 weeks to 44 weeks or later. As long as the infant needs to be maintained in oxygen or other life support lines, behavioral manipulations are often inappropriate and additionally stressful. Under these circumstances, more can probably be learned from close behavioral observation of the infant in the course of routine care, and inferences as to the appropriateness of environmental changes can be drawn from such observations. A systematic approach to accomplish this is currently being developed.

Figure 13
Summary Scales: Scoresheet III of the APIB

SCORE SHEET III - BEHAVIORAL SUMMARY SCALES

PHYSIOLOGICAL PARAMETERS					MOTOR PARAMETERS			
TREMULOUSNESS	BMBAS				TONUS	BMBAS	Balance	
STARTLES	BMBAS				MOTOR MATURITY	BMBAS	Threshold	Postural Central Symmetry
SKIN COLOR	Libility of Head Color	Libility of Corp Color	Threshold	Juandice	ACTIVITY	Spontaneous Activity	Excited Activity	BMBAS
SAILES	APIB	BMBAS			HAND-TO-MOUTH FACILITY	BMBAS		

STATE PARAMETERS					STATE REGULATION			
ALERTNESS	Degree (B)	Degree (A)	Quality	Am't Manipulation	Libility	Range and Flexibility	BMBAS	

SELF REGULATION PARAMETERS									
WITHDRAWAL OR AVOIDANCE BEHAVIOR	CATALOG OF REGULATION MANEUVERS				APPROACH OR GRIPPING BEHAVIOR	CATALOG OF REGULATION MANEUVERS			
	Spit-ups	Gags	Hiccoughs	Bowel Mvt		Tongue Extension	Hand on Face	Sounds	
	Grimaces	Arching	Finger Splay	Airplane		Hand Clasp	Feet Clasp	Fingerfold	Tuck
	Salute	Sitting on Air				Body Movement	Hand to Mouth	Grooming	Leg/Foot Bracing
	Sneezing	Yawning	Sighing	Coughing		Mouthing	Suck Search	Bucking	Hand Hold
QUIETING	Averting	Frowning				On Face	Looking	Cooring	
	Self-quiet (B)	Self-quiet Meter (A)	Complacibility (B)	Complacibility Meter (A)					
PEAK OF EXCITEMENT	BMBAS								
RAPIDITY OF BUILD-UP	Rapidity (B)	Rapidity (A)							
IRRITABILITY	Irritability (B)	Irritability (A)							
ROBUSTNESS	Robustness								
CONTROL OVER INPUT	Control Over Input								
FACILITATION STIMULATION	Facilitation Stimulation								

SUMMARY ATTRACTIVENESS

Administering and Scoring the APIB

The in-hospital preterm APIB examinations should be performed in a quiet, warm (at least 80 degrees F.) room where lighting is indirect, soft and adjustable. The administration of the examination itself takes approximately 30 to 45 minutes or somewhat longer. For the robust infant on 4-hour feeding cycles, the examination should begin with the infant asleep about midway between two feedings (Brazelton, 1973). For the less well-organized infant, it is usually better to come closer to the next feeding as this appears to facilitate state manipulations from the outside.

The APIB scoring manual is the result of several revisions and expansions of earlier versions developed in the course of our intensive work with preterm and otherwise at-risk infants over the last seven years (Als, Lester, & Brazelton, 1978, 1979; Als, Tronick, & Brazelton, 1975). The scoring takes less than 1 hour after training and experience, including the graphic display of the systems scores. The APIB reliability criterion is modeled after that for the BNBAS. For each of the score sheets separately, 90% of the respective 9-point scales need to be within 1 score point between scorers. For 4-point scales, 90% need to be exact to the point. This represents a minimum criterion. Ideally, on the System Sheet, no more than two scales of the 81 9-point scales will differ by two points or more. Of the 76 9-point scales in the Package and Maneuver Section (Score Sheet II), no more than two may differ by two or more points. For the 50 Systematically Elicited Movements Scales (4-point scales), no more than five will differ by one point. Of the 38 behavioral 9-point Summary Scales, no more than two will differ by two or more points. In the catalog of 34 regulation maneuvers scored on 4-point scales, no more than four will differ by one point. This level has been successfully achieved by several trainers. Training in the scoring procedure of the APIB manual is facilitated by reliability in the administration and scoring of the BNBAS, yet this is not mandatory. Further extensive training in behavioral observation of the additional parameters to be scored is obviously required.

Training in the administration of the APIB examination to preterm infants requires prior extensive training in the care and handling of preterm infants in the special care nursery. For the non-medically trained researcher or clinician, this presupposes the establishment of an interdisciplinary work environment fully backed by the neonatology and nursing personnel. Behavioral observations and manipulations otherwise may add to the already massive barrage of inappropriate stimulation brought to bear on the infant and will potentially inflict more harm than good. Once the behavioral researcher or clinician has a good knowledge and understanding of preterm infants' medical and physiological issues and is competent in performing routine caregiving (e.g., changing diapers, feeding, cleaning, bathing) behavioral observation training can begin. The most important aspect of this training is the continuous monitoring of the infant's subtle signs of stress and availability, so that decisions concerning modification of behavioral manipulation, increase of support, or cessation of stimulation can be made reliably and appropriately. The most counterproductive procedure would be to force infants through an entire examination for the sake of scoring all items when, in fact, their behavioral displays indicated clearly that they have reached their threshold of integrated organization and need to be kept quiet and undisturbed. This, in and of itself, is much more important information than a

sheet full of item scores and is recordable on the System Sheet. The most important goal of training is to become experienced, accurate and confident readers of the varied cues of the infant and sensitive interactors who are aware at all times of the impact of their own actions, movements and state on the infant, and who know how to modify, pace and structure their own behavior resourcefully in accordance with the infant's organization. A full training guide to the use of the APIB is currently being developed.

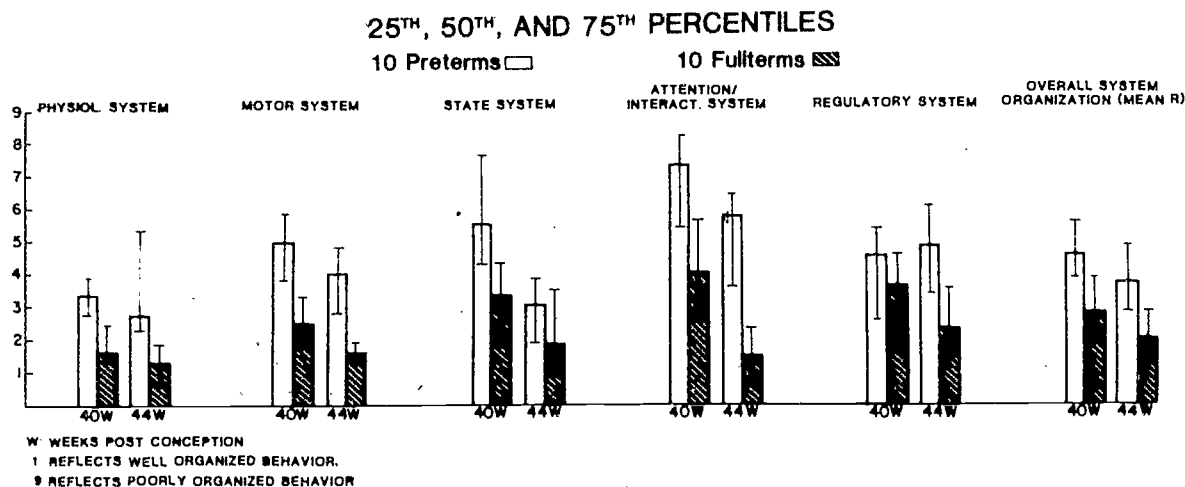
Exploratory Group Comparisons

The usefulness of the APIB in identifying relative behavioral organizational issues in preterm and full-term infants is demonstrated when one examines data from a subsample consisting of 10 preterm and 10 full-term infants of a larger longitudinal study (Als, in press). The preterm infants selected were born before 34 weeks post-conceptual age (PCA), free of known congenital anomalies or known central nervous system insults, and examinable by at least 40 weeks PCA. The full-term infants selected were free of any known complications.

All the preterm infants in this study were examinable by at least 36 weeks PCA, indicating their relative robustness. Inter-rater reliability in administration and scoring of the APIB was maintained in accordance with the criteria spelled out earlier. Figure 14 shows the APIB System Sheet scores for the 10 preterm and 10 full-term infants at 40 and 44 weeks PCA. The median score is presented as a measure of central tendency and the 25th and 75th percentiles as indicators of sample variability. The lower the score, the more well-differentiated and well-organized the performance.

Figure 14

APIB Systems Scores for 10 Preterms and 10 Full-terms
Examined at 40 Weeks and at 44 Weeks Post Conceptual Age



The 10 preterm infants appear more poorly organized than the full-term infants at term equivalent and at one month postterm in all systems. Inspection of Figure 15 indicates that all packages of manipulation also appear consistently more taxing to the 10 preterm infants in terms of system organization than to the 10 full-term infants, both at 40 weeks and at one month postterm. Figure 16 indicates that the kind of examiner facilitation necessary to maintain and support the preterm infants in the course of the package's manipulations is consistently higher than the facilitation necessary for the full-term infants, especially at 44 weeks. It appears that the APIB System and Package Sheet scores differentiate the organizational abilities of the 10 preterm from the 10 full-term infants during manipulations at 40 weeks and at 44 weeks. Overall, the preterm infants emerge as more highly sensitive and easily overreactive to environmental inputs, more easily stressed and overstimulated, and necessitating more finely tuned, sensitive environmental structuring and support in order to free up maximally differentiated performance. Although individual capacities such as visual tracking are quite comparable by 44 weeks PCA, the behavioral organization embedding the capacities is consistently different.

Figure 15

APIB Package Scores for 10 Preterms and 10 Full-terms
Examined at 40 Weeks and at 44 Weeks Post-Conceptual Age

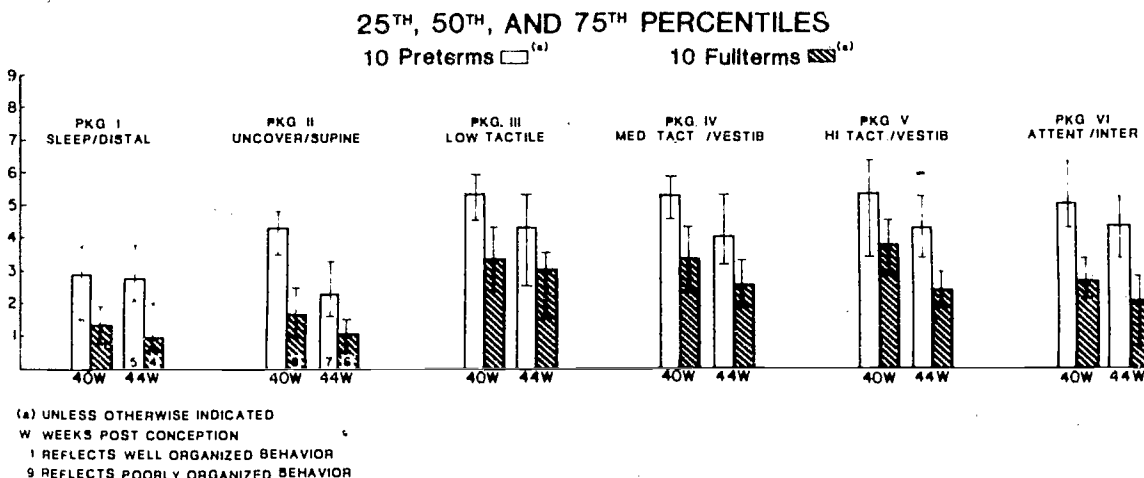
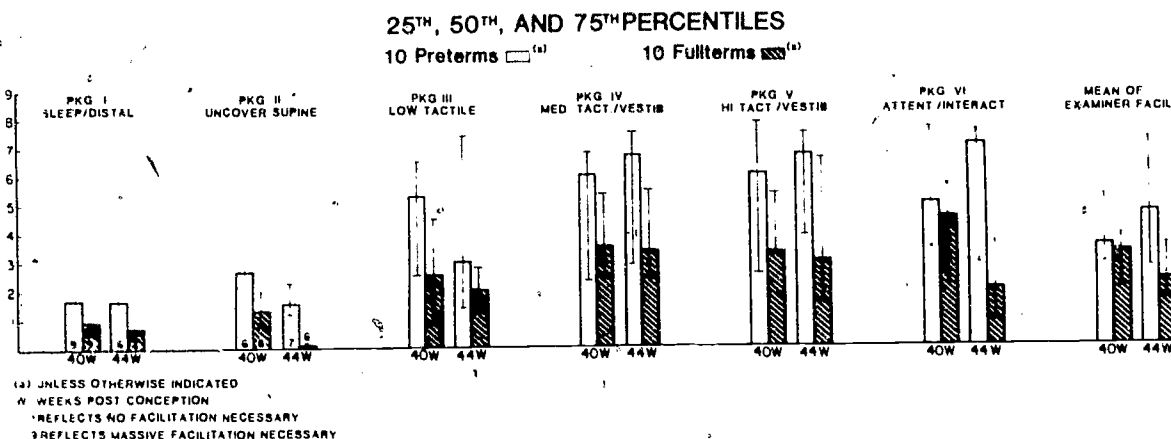


Figure 16

APIB Examiner Facilitation Scores for 10 Preterms and 10 Full-terms
Examined at 40 Weeks and at 44 Weeks Post-Conceptual Age



Individual Patterns of Organization

An important question in interpreting APIB scores is how to identify systematic patterns of behavior which enable the scorer to group or cluster infants on the basis of similar behavioral configurations, rather than on the basis of their prematurity or full-term status. The identification of such patterns would permit one to classify any individual infant into one of these clusters and would provide a benchmark for prediction (Als & Duffy, in preparation). To this end, we have explored the possibility of applying a clustering analysis system called the TICAS system (Taxonomic Intracellular Analytic System), developed by Bartels and Wied (1973, 1977) for the detection of groups of cancerous lymphocytes within a group of normal lymphocytes.

On an a priori basis in this preliminary analysis, 17 features were selected from the APIB which were thought to contribute to the differentiation of groups of infants on the basis of behavioral configurations. Eight of these were taken from the Systems Sheet and are believed to represent comprehensive individual subsystem organization and overall system organization. The "R" Scores only were considered (referring to systems organization during the administration of a package) since they are the most representative scores. The B (Baseline) and P (Post Package Status) Scores were not considered at this point. One feature was taken from the specific package and maneuver scales of the APIB (Score Sheet II) and eight from the Behavioral Summary Scores (Score Sheet III). In deriving features for the TICAS analysis, none of the preliminary features were eliminated on the basis of failure to show significant group differences on the above described early exploratory studies. Features were included or excluded only on the basis of theoretical considerations. For our study of the 10 preterm and 10 full-term infants examined at 40 and 44 weeks, the mean of each of the 17 features described from the 40 and 44 week examination was used.

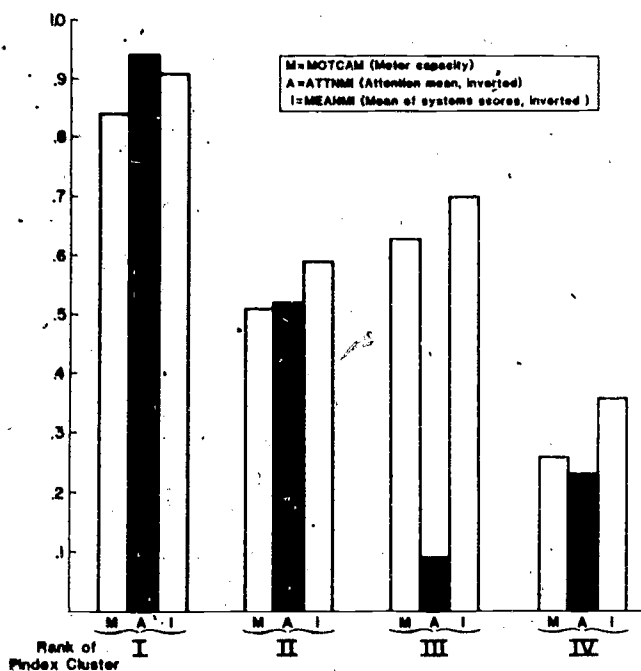
Four clusters or nimbulooids of infants were identified from this study using the TICAS method (Als & Duffy, in preparation) and were ranked on the basis of their relative scores. It was found that the cluster with the highest rank contained seven full-terms and no preterms, and the cluster with the lowest rank contained one preterm and, surprisingly, one full-term. The wider distribution of the preterm group among the clusters suggests, as one might expect, that it is a behaviorally more heterogeneous population.

Figure 17 shows the centroid values of the three best features by cluster or nimbulooid of infants. In Nimbulooid One are infants whose motor capacity scores, attentional capacity scores and overall subsystem organization scores are very good. Seven full-term infants achieved this nimbulooid status. In Nimbulooid Two are infants whose motor capacity scores, attentional capacity scores and overall subsystem organization scores are in the midrange. Four preterm and one full-term infant achieved this nimbulooid status. In Nimbulooid Three are infants whose motor capacity scores and overall subsystem organization scores are above average, but whose attentional capacity is still very poor. One preterm and one full-term infant are in this nimbulooid.

In Nimbulooid Four are infants whose motor capacity, attentional and overall systems organization scores are low. One full-term and five preterm infants are in this nimbulooid. It is encouraging to find that nimbulooid membership cuts across the medical classification of preterm and full-term status and appears to yield conceptually meaningful, behaviorally distinct subgroups of infants.

Figure 17

Cluster Centroids of 4 Nimbuloids Derived from 3 Best APIB Features
(N = 20)



Behavioral Organization of the Older Infant (Kangaroo Box Paradigm)

If the theoretical model of synactive behavioral organization with the key parameters of differentiation and modulation is useful in identifying individuality over time, then a paradigm designed to assess the infant's status along these parameters at a later age should yield a cluster membership distribution similar to that found earlier.

Two paradigms were used: one consisting of face-to-face play of parent and infant and applicable between 1 and 5 months (Als, 1979a,b; Als, Tronick, & Brazelton, 1979; Brazelton, Koslowski, & Main, 1974; Brazelton, Tronick, Adamson, Als, & Wise, 1975; Tronick, Als, & Adamson, 1979; Tronick, Als, Adamson, Wise, & Brazelton, 1978); and one newly-developed paradigm applicable at 9 and at 18 months postterm (Als, in press; Als & Brazelton, 1981; Als & Duffy, in preparation). In our preliminary analyses which focused on the 9 and 18 months observation at these ages, the newly-developed paradigm involves a toy task using a transparent plexiglass box accessible through a transparent mobile porthole latchdoor and containing a hopping, wind-up kangaroo. The box is placed on the floor of a playroom. When the infant can walk, it is placed on a specially constructed stand. This makes the K-Box Paradigm appropriate from the time the infant is able to begin to move on the floor to approximately two years of age. During the observation, all other distractions (pictures, chair, etc.) are removed, and mother and infant are asked to go into the room and play with the toy in whichever way they have the best time (Figure 18). They are observed and videotaped with a two-camera split-screen system through a one-way mirror wall for six minutes. Then the mother is asked to place the kangaroo back into the box, close the latch door and sit against the wall of the room looking at the infant but not interacting with or reacting to him or her (Figure 19). The infant is observed in this stillface situation for six minutes. Then a three-minute reunion is observed when the mother is again allowed to play with the infant.

Figure 18

K-Box "Play Episode"

Photographs taken off videotape of a 9-month-old infant who just has attained the kangaroo and wants to give it to her mother

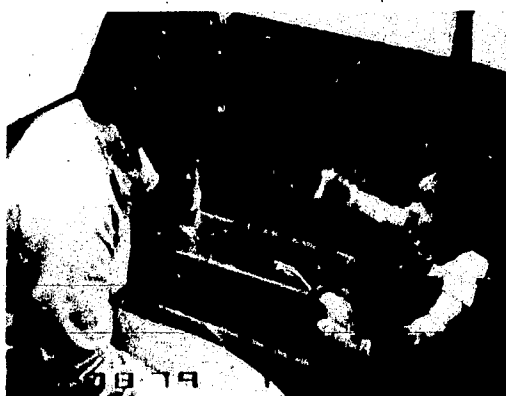
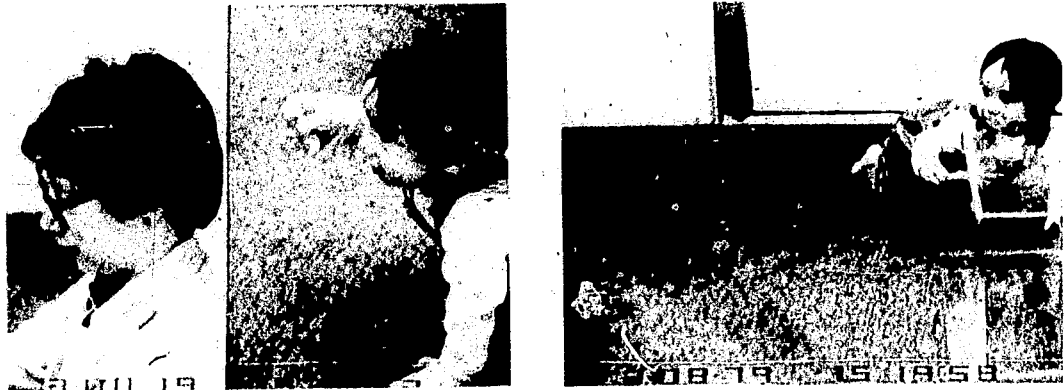


Figure 19

K-Box "Still-Face Episode"

Photographs taken off split screen videotape of a 9-month-old infant who is attempting to engage the mother into play. The mother is instructed to maintain a still face.



The Kangaroo Box Paradigm challenges the infant's cognitive, gross and fine motor, social, and affective capacities and, for some more stressed infants, even their physiological regulations, as they attempt to retrieve the kangaroo from the box. Furthermore, it provides an opportunity to observe the mother's strategies in facilitating and expanding the infant's competence. Some mothers simplify the task for their infants by taking the kangaroo out for them, then winding it up, so that the children are playing only with the kangaroo in that way. If the infants want to explore the box, they may use the box alone as a toy but not combine the kangaroo and box. Other mothers will aid their infants in figuring out how to open the latch door, then aid them in getting the kangaroo through the latch door and winding it up. They may then restart the sequence for or with the infant and develop a complex turntaking cooperative game. The stillface situation highlights the infants' ability to negotiate this challenging task on their own, yet in the presence of the mother. Some infants become assertive and competent in the absence of the mother's attention; others will try to call on the mother for help once their own initial efforts have failed. Others will become very intense and frustrated, focused on the task, unable to solve it and simultaneously unable to move away from it. The more well-modulated infant typically takes some time out, explores the room and then returns to the task. <

We scored the infant's capacities during the play episode along 12 dimensions on a scale from 1 (minimal) to 5 (optimal), yielding a total score ranging from 12 to 60. The dimensions scored include: physiological organization; gross and fine motor organization; symmetry of tonus, movement and posture; apparent cognitive functioning; language and vocal organization; affective organization; social-interactive organization; competence in play with the object; competence in combining object play and social interaction; degree of self-regulation; degree of facilitation and structure necessary; and degree of pleasure and pride displayed by the infant. Attention is paid to autonomic reactions, movements, tone, vocalizations and facial expressions in their interplay. The parent is scored on eight parallel dimensions, also on a scale from 1 (minimal) to 5 (optimal), yielding a total score ranging from 8 to 40. The dimensions scored include quality of parent's motoric input, social input, facilitation, ability to regulate toy task, etc. Three summary interactive items--degree of playful turntaking, overall synchrony of the interaction, and overall quality of the interaction--are also scored. From the stillface episode, 11 infant scores are derived, yielding one total infant score and one parent score. There is one summary reunion score (Als & Berger, 1980). The K-Box Scales are developed to be directly related to the assessment scales of organizational capacities on the APIB.

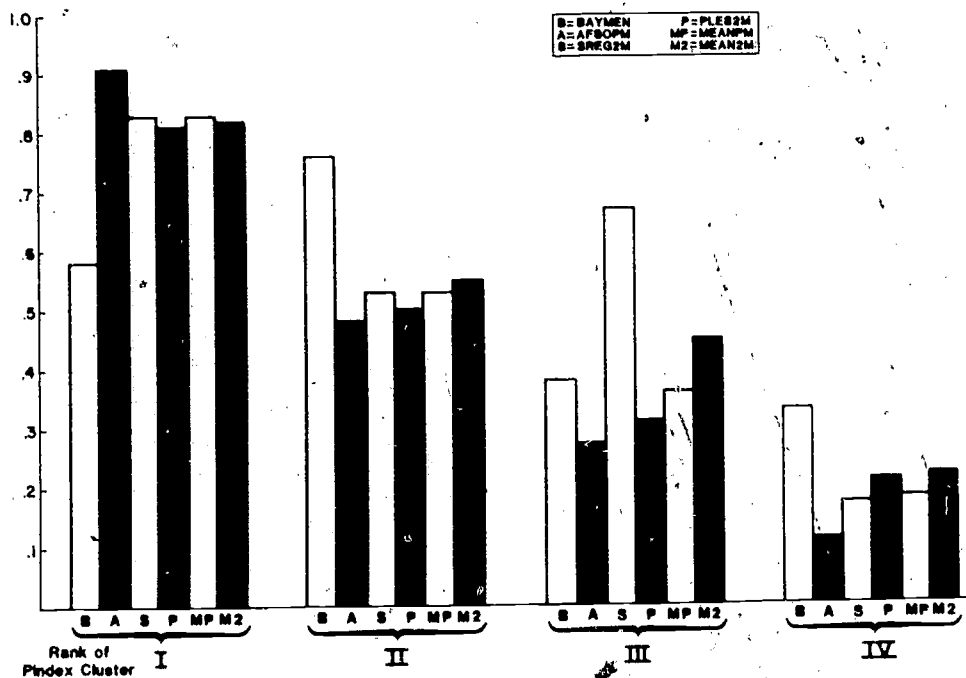
We investigated the possibility of identifying clusters of infants at the 9-month age point with the TICAS system on the basis of competence as derived from the K-Box Paradigm (Als & Duffy, in preparation). Our study group consisted of 20 preterm and 19 full-term infants observed at nine months post-expected due date in the Kangaroo Box Paradigm and also tested on the Bayley Scales of Infant Development. All 39 tapes were scored by a trained but "blind" scorer who was not familiar with the infants as newborns. The 10 preterm and 10 full-term infants discussed above are a subsample of this larger sample.

As we had hypothesized on an *a priori* basis from our model of development, the degree of flexibility in integrating social and object play was the strongest feature in developing clusters. Also, several of the affective range features had good differentiation power, with pleasure and pride being the third best, after self-regulation and fine motor coordination, with flexibility contributing to the differentiation. "Pleasure and pride" is conceived as the ability to set a goal for oneself, attain it, realize the attainment and take pleasure and pride in this attainment. It reflects the closing of an intraorganism feedback loop, which we postulate is a key feature of integrated, autonomous development. It makes the attained achievement over time available to be called upon more and more readily until it is part of the organism's basic repertoire, thus freeing up energies for the next level of goals.

When we added the Bayley Mental Development Index (BAYMEN) which significantly differentiated the 20 preterms from the 19 full-terms, these features from the K-Box Paradigm appear to add important separate dimensions of competence in identifying clusters of infants. The four resultant clusters of infants are shown in Figure 20.

Figure 20

Cluster Centroids of 4 Nimbuloids
Derived from 6 Best K-Box and Bayley Scale Features at 9 Months
(N = 39)



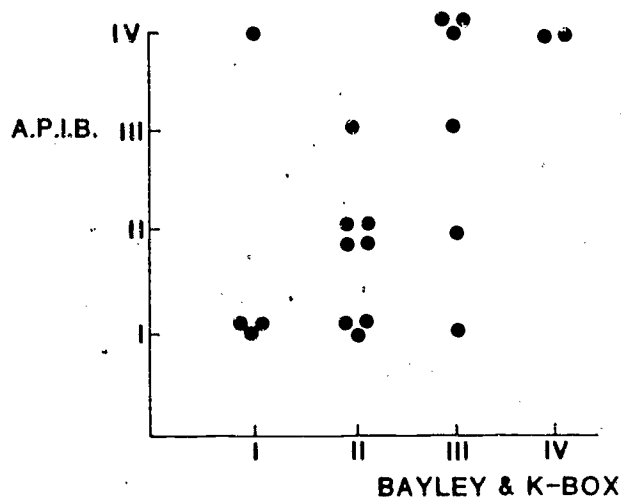
Cluster or nimbuloid membership again cuts across the medical classification of preterm and full-term status and appears to yield conceptually meaningful, behaviorally distinct subgroups of infants. That the Bayley Mental Scale scores are modified by distinct configurations of behavioral parameters encourages us to hypothesize that the predictability of the Bayley Scale can potentially be improved by these functional differentiation and modulation measures.

Correspondence of Newborn Status and 9-Months Status

Cluster classification stability from the newborn period to the 9-month point in our study (Figure 21) demonstrates that there is a highly significant rank order relationship of behavioral competence cluster membership from the newborn period to nine months. Only two outlying infants are identified, one who moved from newborn status 4 to 9-months status 1 and one who moved from newborn status 1 to 9-months status 3.

Figure 21

Correspondence of Newborn and 9 Months Nimbuloid Membership
APIB to Bayley with K-Box



We are very encouraged by these results from our pilot work, since they indicate that it is indeed possible to identify behavioral patterns of competence which have continuity and which cut across medical variables such as prematurity and full-term status. The identification of such patterns will make the diagnosis of an individual infant's developmental issues more succinct. In addition, it will give us a handle on how to structure appropriate early support and intervention and how to measure their effects.

SUMMARY

From our considerations and studies, we have arrived at the formulation of a synactive theory of development, postulating that at any stage in development there is a drive for modulation and integration of subsystem functioning fueled from within the organism and impinged upon, facilitated or potentially hindered by the environment. From fetal development on, the goal of the organism is to actively structure its environment to allow successive reintegrations, following expansion and differentiation. The degree of organism differentiation and the degree of openness of the band of modulation as newly emerging developmental agenda are being negotiated becomes the main dimension of individuality. It appears from our work with newborns and young infants that we can provide more appropriate environmental input by considering seriously infants' thresholds of

integration and strategies of reorganization and self-regulation at each level. It also appears that allowing infants to develop and practice their active, self-instituted return to modulated balance will autonomously close the hierarchical feedback loops of goal setting, goal accomplishment and the realization of goal attainment; and this makes the behavior loops increasingly easy to institute. If we give the grappling organism just as much help as it needs, (not to prevent the grappling but to accomplish a goal it is trying to attain as much on its own strength as it can) we assure the gradual and open progression of increasingly modulated differentiation.

We are all familiar with preterm infants in their isolettes, struggling, grasping and moving until they are finally tucked into the corner of the isolette, shoulders, back and head pressed against the wall, actively seeking help with motor inhibition and reflexion. As they achieve this via the physical barriers of the isolette, their struggle finally ceases, their frantic movements relax, become smooth and subside. The infants' respiration becomes modulated and they can fall into a well-organized sleep state. How often have we then moved them back into the center of the mattress, forcing them to go through the whole rebalancing process over and over again. If we recognize the infants' active efforts and respect their competence, then we can help them accomplish their current goals using their own emerging skills and putting them increasingly at their service. If we do not respect their competence and do not understand their active self-organization efforts at each stage, we may continuously overload them or mistreat them and force them to expend their energies on costly shutting-out mechanisms. This will limit their experience of increasing self-regulation and differentiation and force them to fall back again and again on poorly modulated, bare subsistence mechanisms.

As we allow ourselves to see the integrative complexity of the organism at every stage, we learn how many of the problems of preterm infants are induced by our unwitting overriding of their own active efforts, and how much, therefore, is preventable as we become better at identifying and supporting these infants in their own efforts at autonomic, motoric, state and attentional regulation. A fuller appreciation of the interactive complexities of intraorganism subsystems and organism-environment synaction institutes the possibility of much prevention and the opportunity for much support.

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NEW FACES AND APPROACHES IN THE INTENSIVE CARE NURSERY: THE ROLE OF THE DEVELOPMENTAL/EDUCATIONAL SPECIALIST*

Nancy Sweet

There are three categories of newborn nurseries: 1) the normal newborn nursery, where most newborns put in their brief appearance; 2) the intermediate or secondary care nursery, which can meet some special health support needs of premature and ill newborns; and 3) the tertiary intensive care nursery (ICN) which has highly specialized life-support systems and staff trained to deal with the most serious neonatal complications. Infants in need of these life-support resources are transported from primary and secondary care nurseries to the tertiary ICN serving their geographical area. Infants may remain for days, weeks, even many months in the tertiary ICN. Depending on their course of recuperation, these infants may be returned to secondary care facilities for an additional recovery period, or they may be discharged directly to their homes.

In California, the current estimate is that 5-8 percent of the newborn population is receiving intensive care. The vast majority of infants in the tertiary ICN are premature infants. Our nursery, for example, is a 40-bed tertiary ICN which serves more than 30 primary and secondary hospitals in Northern California. Approximately 500 newborns are admitted each year; 85% of these are less than 38 weeks gestational age; a growing number are less than 30 weeks gestational age; and some are as young as 24-26 weeks gestational age. Twenty-five percent of these infants weigh less than 1,500 grams (roughly 2 pounds) at birth. Their medical problems include those correlated with prematurity, such as respiratory distress, anoxia, retrolental fibroplasia, and other acute problems such as infection, and heart, digestive, and neurological dysfunctions or instabilities. There are, in addition to premature infants, full-term infants with complications, such as those who are small for gestational age, have acute infections, require surgery, show life-threatening congenital anomalies, or have suffered brain or other damage at birth.

To promote the optimal survival of these newborns, the intensive care nursery combines the ultimate in medical technology with a highly specialized, multidisciplinary staff. This includes a variety of physicians (neonatologists, pediatricians, neurologists, cardiologists, surgeons and other specialists) and around-the-clock nursing staff. It may also include social workers,

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physical/occupational therapists, respiratory therapists and additional technical and support staff. The ICN is often a hectic, congested setting, in which the infants are far outnumbered by staff.

For all infants in the ICN, massive medical intervention and multiple interveners are life-saving necessities. Survival is the immediate issue, and medical attention receives first priority. However, in addition to medical intervention, there is growing recognition of the need for developmental/educational intervention for these infants. (In this setting, the concept of education must be somewhat redefined. Just as an infant is not merely a smaller version of a four-year old; so a newborn is not merely a smaller version of a twelve-month old; capacities, signals, and responses are qualitatively different. The concept of teaching must give way to other, more age-appropriate forms of developmental intervention such as provision of supplemental stimulation, modification of the physical environment, and facilitation of social interaction.) Because the extreme stresses of the ICN environment affect the infant's caregivers as well, developmental intervention may also address the needs of parents, hospital staff and other professionals in the field.

To coordinate such intervention programs, a growing number of hospitals are adding a new professional to their ICN staff: the developmental/educational specialist. Both the profession and the programs are new and controversial; there is great variation in the way they are approached and defined. In this chapter we will examine some of these differences and some of the commonalities. We will begin by looking at some of the research which points toward the need and effectiveness of early developmental intervention. Then we'll review the many variable components of nursery intervention programs. The third section examines the philosophy of intervention in the ICN and the roles which these new specialists may play. The fourth section addresses the crucial issue of gaining acceptance in the ICN, and finally, there is a summary of the competencies which all developmental/educational specialists must have.

RATIONALE FOR ICN INTERVENTION

Over the last 25 years, there has been a proliferation of studies and research on infant development, including, in the last decade especially, increasing attention to premature neonates. This research has helped bring about improved neonatal care and dramatic increases in the survival rate of premature and high-risk infants. It has also lent support for the value of early developmental intervention programs and the importance of the developmental/educational specialist role. Three current lines of research have particular relevance to our work in the ICN.

Developmental Outcomes. One justification for early intervention as a preventative measure comes from longitudinal studies of high-risk infants. All studies find these infants to be at risk for later handicapping conditions. In their review of these studies, Kopp and Parmelee (1979) report that 5 to 40 percent of the premature infant population have had moderate to severe impairments and

that in industrial countries, under improved neonatal medical care, the incidence of impairment has dropped to 5-15 percent. Some current research (Hunt, in press) suggests that the longer these infants are followed, the higher the number of mild to moderate impairments identified. There is some evidence, still controversial, that early intervention may prevent or ameliorate some emerging handicapping conditions (Kormer, 1980; Masi, 1979).

The Parent-Infant Relationship. A second significant line of research is concerned with the impact of prematurity and other high-risk conditions on the formation of the parent-infant relationship.

Clearly, the experience of parents whose infants have been placed in the ICN is very different from that of the parents of full-term, healthy newborns. The first view of the ICN with its tiny, sick babies and complex machines is a shocking one for most parents. The baby, so different from the one the parents expected, usually is wrapped in a web of tubes, wires and monitors and is closed off in the isolette. The infant is cared for completely by nurses, and the parents may feel that there is no role for them in the ICN setting. Furthermore, the significantly premature infant is characterized by little or no differentiation of state or alert periods and by great instability of physiological organization. They do not respond as normal full-term infants do. As the infants recuperate, mature and gain weight, their behavior repertoires gradually expand. State and other physiological characteristics stabilize and differentiate; alert periods become longer and more frequent. Responses to environmental stimuli and to human interactions become more apparent. However, at discharge some of these infants still require special care procedures from their parents. Even those infants who are discharged close to term with no continuing problems frequently show very different behavioral characteristics than the infant born at term (DiVitto & Goldberg, 1979). For some parents it continues to be difficult to develop a satisfactory relationship with the high-risk infant. These parents may perceive the infant as a difficult child (often justifiably) or themselves as inadequate parents or both. The consequences of these difficulties are documented in reports of higher incidence of child abuse and neglect for high-risk infants (Klein & Stern, 1977).

Klaus and Kennell (1976) presented evidence of the significance of the neonatal period to the attachment between parent and child. They show that the attachment process can be profoundly disrupted by infant malformation, prematurity and separation from the mother at birth. While there is controversy over their argument for a sensitive period in the first minutes or hours of life, there is little dispute that extensive separation as a result of neonatal intensive care, in combination with the infant's neonatal complications, can have a significant negative impact on the parent-infant relationship. This conclusion is supported by the child abuse/neglect statistics mentioned above, as well as by the low parental visitation rates in many ICNs. Parents of hospitalized high-risk infants express common concerns and feelings during, and long after, their ICN experiences. A number of researchers (Brazelton, Koslowski, & Main, 1974; DiVitto & Goldberg, 1979; Field, 1977) have identified and characterized some of the disturbances which may be found in the early relationship between high-risk infants and their parents.

Other studies have examined the effects of parent-infant relationships on the developmental outcome of high-risk neonates. Beckwith and Cohen (1978) have shown that at one month of age, the greater the infant's medical vulnerabilities, the higher the mother-infant interaction rates; and they have identified these interactions as being of primary significance in determining the infant's development. The extensive premature infant studies project at UCLA (Sigman & Parmelee, 1979) suggests that the early caregiver-infant relationship plays a pivotal role in ameliorating or exacerbating infant risk factors. In the studies, caregiver-infant interaction measures were significant predictors of developmental outcomes of high-risk infants at age two.

There is evidence that high-risk infants both affect and are profoundly affected by the parent-infant interaction. Some current studies suggest that early intervention with parents can positively affect the interactions with their infants and thus contribute to the infant's optimal development. Minde, Morton, Manning and Hinds (1980) have identified how perceptions of the characteristics and capacities of the newborn premature infant can influence parental responsiveness to the infant. Several authors suggest that very early intervention may assist parents in understanding the cues and responses of the high-risk newborn, and in interacting with the infant effectively (Als, Lester, & Brazelton, 1979; Field, 1979).

Supplemental Stimulation in the ICN. A third, and perhaps the most significant line of research supporting ICN intervention can be found in studies of supplemental stimulation for the premature infant. As a recent review of this research by Masi (1979) indicates, beneficial effects were generally found to result from a variety of sensory stimulation procedures in 19 studies with premature infants. Benefits varied from weight gain to neurological maturation to behavioral changes. Four of these studies, and a more recent study by Leib, Benfield and Guidubaldi (1980), reported better performance by experimental infants on standardized developmental assessments during the first year of life. Improved developmental performance was found particularly in two studies which continued the stimulation program at home with parental participation after discharge from the ICN (Rice, 1977; Scarr-Salapatek & Williams, 1973).

The original assumption underlying many of these studies of supplemental stimulation was that the intensive care nursery deprived the premature infant of sensory stimulation and interaction with caregivers (Rothchild, 1967). However, this deprivation model was later questioned (Cornell & Gottfried, 1976). The deleterious effects of overstimulation, as opposed to understimulation, in the ICN have now been documented in a growing number of studies of noise, handling and other ICN factors (Blennow, Svenningsen, & Almquist, 1974; Long, Lucey, & Phillip, 1980). The study by Long, Lucey and Phillip (1980), for example, found that 75% of all hypoxic events were correlated with handling procedures. After an observational study of the ICN environment, Lawson, Daum and Turkewitz (1977) suggest that premature infants may suffer from an inappropriate pattern rather than an inadequate amount of stimulation.

Sound arguments are presented in the work of Gorski (1980, in press; Gorski, Davidson & Brazelton, 1979) and Als (Als, Lester & Brazelton, 1979; Als, Lester, Tronick & Brazelton, in press) that the greatest concern of ICN intervention must be developmentally appropriate stimulation for the individual infant. The match of environmental and caregiver stimuli with the infant's maturational, medical and individual capacities may have tremendous impact on the development and perhaps even the survival of the high-risk newborn. Taking the research literature as a whole, there is evidence for increasing some forms of stimulation, decreasing other forms, and modifying the infant's experiences to best meet developmental and individual needs.

COMPONENTS OF NURSERY INTERVENTION PROGRAMS

Studies in each of the three categories are helping to confirm the value of early intervention programs in promoting high-risk infants' optimal development. These intervention programs may be structured in a variety of ways.

Perhaps the most significant determinant of the structure of the intervention program is the size and type of nursery. Some hospitals have all three levels of care, while others may have primary only, primary and secondary, or tertiary only. The type of intervention program which is appropriate for a large, complex ICN may be very different from one that is appropriate in a community hospital where a large number of babies are born, a few receive intermediate care, and seriously ill babies are transported elsewhere. Current nursery intervention programs differ in target populations, period of intervention, staffing, service delivery systems and intervention goals.

Target Population. Though all very early intervention programs are concerned with high-risk and handicapped newborns, the specific target population may vary. Some programs work only with premature and other categories of high-risk infants. The target population may be even more specific, particularly in the large ICN; it may include only the subgroup which meets certain risk criteria, or only those premature infants who are past a certain gestational age. For example, our ICN intervention program at Children's Hospital in Oakland, California admits high-risk newborns with an anticipated ICN stay of one month or more. This amounts to roughly 10% of the ICN's annual population of 500 infants.

Some programs are concerned only with those newborns identified as having a known or suspected handicapping condition. These programs are often located in general community care hospitals or in large hospitals with all three levels of neonatal care, which are often teaching institutions for affiliated medical schools. Programs of this type ordinarily begin services at discharge rather than in the ICN and may combine screening and intervention programs. The reason for this is that most handicapped infants who can be identified at birth are not found in the ICN setting. Many newborns with recognizable genetic disorders such as Down's Syndrome and even spina bifida do not require intensive care at birth. Though a few of these infants may require an ICN stay, most of the handicapped infants who can be identified in the ICN are those with brain damage resulting

from anoxia, those with neonatal infections such as rubella or CMV and those with multiple congenital anomalies which are both life-threatening and handicapping. This group of infants constitutes a small percentage of the ICN population.

Although the infant is always the central focus of a nursery intervention program, other target populations may be identified as crucial to effective intervention with the infant. A program may work with any or all of the following: 1) infants, 2) parents, 3) nurses, 4) other related disciplines within the hospital or 5) agencies and professions in the community which may provide follow-up services. Some intervention programs work only with and through parents. Others train nurses as primary interveners with infants. Still others may be concerned with comprehensive, coordinated discharge planning and neonatal follow-up.

Period of Intervention. The timing and duration of very early educational intervention also varies from program to program. Intervention may begin when the infant is admitted to the ICN or later in the ICN stay, either when the infant has reached a certain maturational age or when the infant is identified as meeting certain eligibility criteria, such as exhibiting a potentially handicapping condition. Some programs begin only when the infant is ready for discharge to a secondary care setting or to the home. Some intervention programs last only as long as the infant is in the ICN or the hospital setting. Others (which we anticipate to be the most effective) continue intervention or at least neonatal follow-up during the first months or years of life. For example, for the last several years California has had six high-risk infant follow-up model programs which, with a variety of designs, provided effective home-based intervention during the first year of life. Several states, such as Florida and California, have provided funds for developmental assessment during the first year of life for all infants meeting certain risk criteria at birth.

Service Delivery System. Programs also differ greatly in their service delivery system--the component services which are actually provided as part of the ICN intervention program. The service delivery system may include a support group for parents, a training program for ICN nurses, multidisciplinary case review, neonatal assessments or other in-hospital services. Follow-up services, when they are offered, may include coordination of discharge planning, parent education at home, developmental monitoring, well-baby check-ups, assistance in finding community resources, or other services.

Different combinations of services are offered by programs with different staffing patterns and intervention philosophies, and in different hospital settings. We have little evidence yet as to which types of services are essential to effective intervention.

Staffing. ICN intervention programs differ in staffing structure. Some programs use ICN nurses, social workers, psychologists and/or physicians performing specialized developmental intervention functions in addition to their regular ICN duties. More and more frequently, coordination of intervention efforts is the responsibility of a single developmental/educational specialist. The specific duties of this new professional role vary from program to program.

Developmental specialists may work directly with the infant in the ICN (which we will refer to as the "expert provider" role), or they may work indirectly with the infants, by training nurses or parents to work with them. (This we will refer to as the "facilitator" role.) These represent opposite ends of a continuum of functions; many specialists perform some combination of the two. Their roles are intimately related to their program's intervention philosophy, and will be explored further in the next section.

Intervention Goals. All intervention programs for high-risk infants have as primary goals the prevention or minimization of handicapping conditions and the encouragement of optimal infant development. Beyond this common broad purpose, however, early intervention programs have very different specific intervention goals. ICN intervention programs may define their goals as providing supplemental stimulation for ICN infants, as providing support for parents of prematures, as sensitizing nurses and other staff to the developmental needs of the infant in the ICN, or as providing comprehensive follow-up services to the infant at risk.

Clearly, the specific intervention goals are shaped by the individual program's setting and history of evolution. For example, the hospital setting imposes constraints not encountered in other types of infant intervention programs. Medical procedures and needs come first for these infants; developmental efforts and intervention goals must be adapted to the medical necessities. The functions of the developmental/educational interventionist must be compatible with those of existing professional disciplines in the individual hospital.

A note of caution is appropriate here. The specialist role is vulnerable to controversies over the relevance of developmental concerns, the efficacy of early intervention, and the potential dangers of labeling an infant as having special needs. Such controversy is nowhere more lively than in the medical setting in which we seek to establish this new role. To be effective, the developmental specialist must work toward intervention goals which are specific, discrete and compatible with other ICN concerns, with immediate as well as long-term benefits to infants, parents and staff in the ICN setting.

PHILOSOPHY OF INTERVENTION IN THE ICN

The intervention philosophy in most ICNs is derived from the answers to a number of key questions: What do premature and other high-risk infants need in order to encourage their optimal development from birth? What is the impact of the ICN environment on the infant, and how can this be appropriately modified? What effects do high-risk infants and their parents have on each other, and how can parents be assisted in establishing an optimal relationship with their infant? What effects do the high-risk infant and nurse have on one another? What can be expected of the behavior of the high-risk infant, and what importance do individual behavioral differences have?

In order to clarify some of the significant issues, we will look at intervention philosophy in three major areas: 1) approaches for working with ICN infants, 2) approaches for working with ICN parents, and 3) approaches for working with nurses and other professionals.

Approaches for Working With ICN Infants

Philosophies of intervention with the infant in the ICN can be expected to change with results of research. Two current approaches can be identified which we might distinguish as a maturational age versus an individual difference approach. Again, these constitute two extremes of a continuum. On one end are interventions which can be prescribed in a curriculum format based on the gestational age of the infant. A premature infant of 36 weeks gestational age, for example, will be presented on a daily basis with a certain type of visual stimulation. This approach is based in part on the supplemental stimulation research literature. (The EMI Curriculum by Wollens, Elder and Hastings is an excellent example.)

At the other extreme is intervention which is based on assessment of individual infant capacities and needs and which seeks to facilitate the emerging capacity of the neonate to cope with extrauterine life. There is now a wealth of evidence (Osofsky, 1979; Stone, Smith, & Murphy, 1973) that newborn infants are receptive, responsive and capable organisms who are active participants in the developing infant-parent relationship. Much of the research in this area and its applications to an individual-centered approach to intervention have their origin in the work of Brazelton and his colleagues, particularly Gorski, Als, Lester and Tronick (Als, Lester, & Brazelton, 1979; Als, Lester Tronick & Brazelton, in press; Brazelton, 1973, 1979; Gorski, 1979, 1980;). This type of intervention may be as concerned with the reduction or modification of stimulation, or with the emerging patterns of infant-caregiver interaction, as with the provision of supplemental stimulation. This is the approach we have adopted in our ICN Interact Project, which is described in the chapter of this book by Kathy VandenBerg.

Approaches for Working With ICN Parents

There are several lively controversies in approaches to intervention with parents of infants in the ICN. One is whether and how parents should be involved in developmental intervention. ICN intervention programs range from little or no parent participation to emphasis on parents as primary interveners from the beginning. Some programs may involve little regular direct work with the infant, concentrating instead on parent support and parent education prior to and after the infant's discharge from the ICN.

A second controversial area is the formation of the parent-infant relationship when the infant is premature or at other risk. Current studies (Als, Lester, & Brazelton, 1979; Field, 1979; Gorski, 1980; Masi, 1979) are addressing such questions as: What is the impact of having a premature infant and of the lengthy

separation required by hospitalization on the strength and quality of the parent-infant bond? Do parents of these infants generally go through a grieving process, and is there a common sequence of changes in the parents' interactions with the baby in the ICN? What is the efficacy of different approaches for working with parents of high-risk infants?

Other issues of particular concern in the establishment of ICN intervention programs include: What are parents' long-term expectations when an infant is born at risk, and how does involvement in early intervention affect those expectations? How can and should the high-risk baby's special needs be presented to the parents? Do we conceive of intervention with high-risk infants as a preventative, time-limited approach with infants who generally can be expected to attain normal developmental status? Or is this a sustained therapeutic approach for children who, because of their high-risk status and the resulting impact on the parent-infant relationship will always have special (though not necessarily special education) needs?

The issue of labeling is a sensitive and serious one. On the one hand we do not want parents to identify their infants as handicapped merely because they are at risk, or have been included in an ICN intervention program. Both may be significant factors in shaping parents' long-term expectations of normality. At the same time we know that some ICN infants do not develop normally. Some will be handicapped; many are likely to demand more sensitivity and patience from their parents in the first year of life. We know that the premature infant (DiVitto & Goldberg, 1979; Field, 1979), the full-term but small for gestational age infant (Als, Tronick, Adamson, & Brazelton, 1976), and, we suspect, the infant with chronic bronchopulmonary dysplasia (chronic lung problems resulting from treatment of respiratory distress) all may pose special challenges to the parent-infant relationship. How do we help prepare parents for these special needs so that they do not interpret difficulties as their failures as parents or as indications that the infant is handicapped?

It seems likely that parents must be treated as individually as the infants, with some balance of educational and supportive resources and allowances for the parents' crisis states and socioeconomic realities. We are aware that parents may have special needs--that, for example, many high-risk infants have high-risk parents (defined by age, medical or socioeconomic status or by all three factors). And we must remember that the parent population may vary from community to community and hospital to hospital.

Approaches for Working With Nurses and Other Professionals

The role of the developmental/educational specialist in the ICN must be defined in relation to those of other professionals already in that setting, as well as by the model, philosophy and goals of intervention. Since the array of professionals involved in ICN care varies from setting to setting, the definition of the developmental/educational specialist must also be expected to vary, especially in the beginning stages of implementing a program.

One variable is the extent to which the specialist is involved in direct handling of ICN infants--the continuum from facilitator to expert provider. As an expert provider, the developmental specialist would interact with each infant in specified ways and for specified periods, often on a daily basis. For example, this might involve providing 15 minutes per day of supplemental stimulation such as visual tracking activities or gentle rocking.

If the intervention philosophy emphasizes modification of the infant's total environment, the developmental specialist may act as facilitator, working with and through the people who provide that environment. As a facilitator, the specialist might determine, for example, that a certain infant is particularly vulnerable to overstimulation during social interaction with an adult. A goal of intervention might then be to encourage the nurses and parent(s) to recognize the infant's stress indicators, and to either talk to or engage in eye-to-eye contact with the infant, but not to do both simultaneously.

Some developmental specialists attempt to combine both direct, expert provider functions and indirect facilitator functions. Other approaches may also be found, such as training nurses as the sole interveners. If the developmental specialist is physically present in the ICN, however, role clarification, particularly in relation to the role of the nurse, will be necessary.

Nurses are the primary ICN professionals with whom developmental specialists must work. In order for their work to be effective, they must understand the responsibilities and stresses of the ICN nurse, and they must shape intervention expectations accordingly. Some important factors are: 1) The nurse's primary responsibility is the medical lifesaving and caregiving for the ICN infant. This requires a great deal of technical skill and attention. 2) The ICN is as stressful an environment for the nurse as it is for the infant. Particularly in a tertiary ICN, both the noise and the demands and tensions of many high-risk infants struggling to survive can take their toll on personnel. 3) The nurse, particularly the primary care nurse, may also be a surrogate parent for the infant. Attachment to an infant receiving primary care is likely, and this means certain emotional jeopardy to the nurse, since the infant will either recover and leave abruptly or die. The nurse may also have to cope with ambivalent feelings toward the parents. 4) Individual nurses vary widely in their ICN experience and in their interest and expertise in developmental concerns. Some nurses pride themselves on their technical and medical skills. Some have the sensitivities and observational skills which make them excellent caregivers as well.

There are other ICN disciplines with which the developmental specialist must work. These vary from hospital to hospital but may include a variety of medical specialists (neonatologists, pediatricians, surgeons, cardiologists, neurologists, etc), therapists (physical, occupational, speech, respiratory) and social workers, as well as personnel from consulting departments such as child development, medical genetics, pediatrics and others.

The specific mix of professions involved in the ICN will determine the turf issues which must be worked out in establishing the developmental specialist role. For example, though physical or occupational therapists may be developmental specialists, ICN intervention is not synonymous with physical or occupational therapy. The differences and additional concerns of early intervention may need

to be specified. Existing therapy procedures must be incorporated into, or at least coordinated with, the developmental intervention program. If the ICN has a social work staff, the developmental specialist must distinguish his/her educational and supportive functions with parents from the social workers' counseling and perhaps discharge planning activities. Finally, developmental intervention programs for infants must be clarified and, ideally, planned with key medical specialists, particularly the neonatologists or pediatricians responsible for medical care. This is essential with the very premature and very ill newborn and with the recuperating infant whose medical status is unstable.

The developmental specialist also can and generally does work with community agencies and professionals involved with high-risk infants after discharge from the ICN. This may include nurses and other staff of secondary care facilities as well as community resources which can be used once the infant goes home. Developmental follow-up should be a concern, whether provided as a component of the early intervention program or coordinated with public health nursing, neonatal follow-up or well-baby clinics, private pediatricians, child welfare services or intervention programs for the handicapped. Planning for these and other services should begin prior to discharge from the ICN and should be multidisciplinary.

What Does the Developmental/Educational Specialist Do In the ICN?

It should be clear that what the developmental/educational specialist actually does in the ICN depends on the type of setting, intervention philosophy, services offered and other disciplines involved. The developmental specialist may work with any or all of five groups: infants, parents, nurses, other ICN disciplines, and community agencies and professionals. Below is a list of specific activities which may be appropriate in different settings. Though not all intervention programs will attempt all of these activities, they include:

With Infants:

- behavioral observation and developmental assessment
- preparation and daily implementation of maturationally appropriate developmental activities, such as activities which encourage visual alerting in the premature infant
- environmental modification, such as placing objects for visual attention in the isolette, or covering the top of the isolette to reduce constant bright light
- recommendations for positioning the infant

- identification of soothing techniques which are effective for individual infants
- preparation for and assistance with feeding
- sensory stimulation, such as visual tracking
- social stimulation, such as holding, rocking or face-to-face interaction
- recommendations for altering care practices which influence development, such as noise reduction, feeding on demand, allowing the baby recovery periods between handling procedures, or switching to a cannula from hood oxygen as soon as possible
- developmental activities for older infants which are appropriate to their age and degree of recuperation
- developmental follow-up and recommendations once the baby leaves the ICN

With Parents:

- initiating and maintaining regular communication with parents who for distance, health or other reasons cannot visit the ICN regularly
- observing the infant's behavior with the parent and demonstrating emerging capacities and responses of the infant
- suggestions of handling techniques appropriate to the baby's maturational level
- encouraging the parent's effective interaction with the baby, such as in soothing or eliciting visual attention
- enabling the parents to play an active role with the baby by suggesting observation and stimulation activities which will provide a basis for parent-child attachment
- preparation for post-ICN expectations in the secondary care nursery and at home

With Nurses:

- recommendations about caregiving practices which facilitate development, such as changing the infant's position in the isolette, knowing behavioral cues which indicate overstimulation, interacting with the alert baby during routine caregiving procedures
- assistance with soothing and feeding problems

- involving the nurse when possible in behavioral assessments, and in planning, implementing and evaluating developmental activities
- providing formal training sessions and information as needed about infant development, attachment, parent involvement and other areas of interest to nurses

With Other Disciplines:

- contributions to treatment and discharge planning and to general transdisciplinary education which occurs during weekly multidisciplinary ICN rounds
- coordination of primary intervention roles with others who may have strong relationships with parents or special therapy responsibilities with the infant, such as the nurse, social worker, occupational or physical therapist
- coordination with nursing and social work in the provision of materials and resources for parents and in parent-to-parent support
- provision of information about community resources available to the family and recommendations about types of programs for handicapped infants, child care, respite care, etc.

The Developmental/Educational Specialist in the ICN Interact Project

Our experiences at the Interact Project serve as an example of one way that an ICN intervention program can be structured. The Interact project is one component of the Child Development Center of Children's Hospital in Oakland, California. This physician-led department has long been concerned with preventive, diagnostic and treatment services for high-risk and handicapped infants. The ICN Interact Project was preceded by and based on several related research, intervention and follow-up programs. More than five years ago, with the active support of ICN neonatologists, the Child Development Center assumed responsibility for developmental assessment and therapy in the ICN.

First one, then a second half-time educational specialist were introduced into the ICN setting. Both were special educators who had worked for many years with handicapped infants and their families. The first had provided home-based intervention to high-risk ICN infants as part of a previous research project. Both were trained in use of the Brazelton Neonatal Behavioral Assessment Scale (Brazelton, 1973).

During the first several years, the educational specialists gained expertise in intervention with increasingly younger premature infants and in the special needs of ICN parents and staff. This expertise provided the basis for the design of the ICN Interact Project, a model program funded by the U.S. Office of Education.

The ICN Interact Project provides developmental intervention for the approximately 10% of the ICN population who will be hospitalized one month or more. Most eligible infants are premature, but a few are full-term, seriously ill newborns. Infants are being referred at earlier and earlier points in their hospitalization, often before they have recuperated sufficiently to be handled for developmental purposes. Many premature infants are referred at 28-30 weeks gestational age.

Developmental intervention begins immediately with behavioral observation, work with the parents and recommendations of individually appropriate care and handling techniques to the primary care nurses. Intervention is then continued in the secondary care hospital as needed and at home during the first year of life.

In addition to the educational specialists, the intervention staff includes a nurse with both Public Health Nurse and ICN experience and two developmental pediatricians. One pediatrician, the medical director for the project, is involved in developmental assessment and case review of infants in the ICN. Both pediatricians are involved in neonatal follow-up examinations scheduled on a quarterly basis.

The educational specialist attempts to discuss the baby's behavior with the nurse each day, particularly primary care nurses. They can talk with the day and evening shift nurses in the unit, and communicate with the night shift by phone or note. The educational specialists also attempt to meet with parents on a regular basis, several times a week if possible. Developmental goals and activities are posted by the infant's bedside so that nurses and parents can carry them out at optimal times for the infant.

Our intervention philosophy is one of identifying and meeting the developmental needs of individual infants by altering their total ICN environment. (This is detailed in the chapter by VandenBerg in this book.) Although our developmental intervention often includes supplemental stimulation, it is equally likely to involve attempts to reduce or modify stimulation. An infant's capacities, cues and responses are assessed by several methods, including a structured observation of physiological and behavioral responses to routine caregiving procedures by the nurse. The educational specialists have developed a modification of the Brazelton Neonatal Assessment to use with prematures. They are beginning to use the Assessment of Premature Infant's Behavior under development (APIB) by Als, Lester, Tronick and Brazelton (in press).

Our educational specialists function more in a facilitative than expert provider capacity. Though they attempt to carry out developmental activities on a daily basis if appropriate, they are particularly concerned with encouraging optimal caregiving practices by nurses and parents.

A specific example of developmental intervention may be helpful. One particularly important goal with premature infants is to help them develop the ability to cope with, respond to, and ultimately initiate social interaction, as a key element in the parent-infant relationship. To this end, the educational specialists may work toward developing physiological and sensory precursors of social interaction, such as ability to maintain a state of quiet alertness and the ability to visually track; they will also be concerned with other factors, such as

effective soothing techniques, or reducing social overstimulation which may lead the infant to close or cover its eyes. Our educational specialists will assess the individual infant's current developmental status and readiness for social interaction. They will also assess the infant's environment in the ICN and the parents' readiness for social interaction with the infant. They will develop and carry out relevant developmental activities such as visual tracking. They will ask the nurse to carry out these activities as well as recommended face-to-face interactions with the baby when possible. They may help the parent know when to expect visual attention from the premature and what to do to help that individual baby achieve an attentive state. They will share with the nurse and parent their observations of how the baby indicates fatigue or overstimulation in social interactions. They will share their observations of developmental progress in this area, and any emerging concerns.

HOW DOES THE DEVELOPMENTAL/EDUCATIONAL SPECIALIST GAIN ACCESS TO THE ICN?

ICN intervention programs have been established in a variety of ways. It often proves helpful to have the initial assistance of at least one physician, preferably within the ICN setting or from another relevant hospital department, but at the very least a pediatric practitioner from the community. This physician can help the developmental specialist explain the need for intervention and follow-up to other medical personnel in the ICN. (An effective presentation of the research supporting this type of effort is helpful.) Former ICN parents may be persuasive advocates; a number of neonatologists have initiated and supported intervention programs on the basis of research and feedback from parents about their ICN experiences. The developmental specialist must be prepared to give a clear description of intervention goals and techniques and anticipated benefits to infants, parents and staff. (The toughest questions will include funding and the distinction among professional roles in the ICN.)

Avenues and obstacles in gaining access to the ICN vary widely from setting to setting. There are at least four essential elements for gaining access which we can identify: 1) developmental expertise, 2) physician support/liaison, 3) nursing support/liaison, and 4) funding.

Developmental Expertise. Obviously, the educational specialist must be an expert in infant development and early intervention. All ICN professionals must become aware of this expertise and gain an understanding of what early intervention is. To accomplish this, the educational specialist must become sufficiently versed in medical terminology and ICN procedures to communicate that expertise effectively. She or he must be up-to-date on research and publications pertaining to high-risk infants and their families. The ICN is a technical place; suggestions which have technical research behind them are most likely to be listened to.

Physician Support/Liaison. The need for physician support should be obvious. The physician has primary responsibility for all treatments in the ICN. In our project the neonatologists and other attending physicians refer infants for developmental

intervention based on the infant's recuperative status and anticipated stay in the ICN, concerns about parent involvement and desire for developmental follow-up. Experiences with individual physicians can be expected to vary widely, but our experience has been that most physicians in the ICN are receptive to a well-designed intervention program, particularly if it has the support of other disciplines in the hospital, such as nursing, pediatrics and/or social services.

In addition to initial and ongoing support of the intervention program by ICN physicians, it is vital that the educational specialist have a physician who can act as liaison with other physicians and serve in a consulting and educational capacity for the specialist. The educational specialist will have many terminology and treatment questions which will affect the intervention plan for individual infants. In our program, the physician makes weekly rounds of project infants with the educational specialist in order to confer on the intervention planning and evaluation. (Participation in these multidisciplinary ICN rounds can have multiple benefit for the educational specialist. It is an excellent opportunity for non-medical personnel to obtain technical information about ICN procedures. It is also an avenue for gaining greater access to the ICN. The educational specialist can contribute his/her expertise in ICN and discharge planning, and in educating other disciplines in developmental/parent involvement areas.)

Nursing Support/Liaison: A separate and equally vital key to gaining access to the ICN is support from and a liaison with nursing staff. This relationship may prove even more essential than the physician relationship to the daily effectiveness of the developmental specialist in the ICN.

For example, our nursing liaison is a clinical nurse specialist with supervisory responsibilities in the ICN. She has strong concerns for developmental issues, the involvement of parents and the optimal functioning of nurses in our ICN. She plays an important role in our efforts to integrate developmental intervention with regular caregiving. She assists the developmental specialist in introducing and evaluating new intervention techniques and in gaining their acceptance by ICN nurses. (This may be done formally during ICN nursing staff meetings either by the nurse liaison or through scheduled presentations by the developmental specialist. It may be done informally by helping the developmental specialist communicate effectively with individual nurses.) Since our liaison nurse is in the ICN on a daily basis, she can also aid coordination of care among all three nursing shifts.

The final, and perhaps most exciting benefit of a nursing liaison, is the potential for joint efforts to improve the ICN environment for all infants, parents and staff. Recommendations from the intervention program can be selected and incorporated by nursing staff into general ICN practices, and infants who are not in the intervention project may benefit. In our own nursery, the intervention project is coinciding with and supporting new efforts by nursing to humanize the ICN. The positive effects of cooperative efforts will be far greater than the intervention project could achieve alone. In our setting, for example, intervention staff are working jointly with nursing and other departments in accomplishing major goals, such as the initiation of a parent support group, design of a new ICN, provision of a support group for ICN nurses, and better discharge planning.

Funding. A major obstacle to gaining access to the ICN may be funding. In California and most other states, the educational specialist is not an established professional discipline in the medical setting. As a result, intervention services cannot be supported by the medical billing system. A lack of funding has constrained the growing interest of many ICN's in developmental intervention and support for ICN parents.

Funding through the Handicapped Children's Early Education Program (HCEEP) provided a major impetus for our program and several other new ICN projects. Soon, of course, we will face the problem of assuring continuation funding. The ideal solution, although a time-consuming one, would be to establish the educational specialist as a recognized, licensed professional in the medical setting. This will require professional standards for the developmental specialist and probably legislative appropriations of public health funds.

An increasing number of teaching hospitals are adding non-medical developmental specialists to their pediatric or neonatology staffs. The department involved thus provides the funding for the developmental specialist role, though the specialist may then have to take responsibility for locating grants.

Training, Feedback, Transition and Assistance

In addition to these four major elements there are several other types of activities which have proven helpful in establishing our program. First, training programs for ICN nurses have been both welcomed and effective. Our training courses have covered such subjects as normal infant development, attachment and basic guidelines for developmental intervention. The provision of these courses prior to initiation of intervention has proved helpful in our own ICN and in secondary care nurseries. It can be a good way for the educational specialist to establish credibility, clarify the role and become a familiar face to ICN staff. Formal training sessions have limitations, but they are good for sharing basic information with many people. For example, during a recent course for our ICN nurses, the educational specialist recommended covering the top of the isolette with a towel to reduce the constant bright light bombarding the baby, and thus to encourage more visually alert periods. It was extremely gratifying to discover almost every isolette in the ICN covered during the next few days and fairly consistently thereafter.

Another strategy which has been effective for our program has been a real effort to provide feedback to nurses and other staff about how infants progress once they leave the ICN. Follow-up information is received eagerly since ICN involvement with a baby is intense and then ends abruptly when the baby leaves the ICN. A poster in the staff lounge, with infants' current photographs and developmental status, has received rave reviews.

A third effective strategy is the attempt to be a link between the tertiary and secondary care nurseries. We hope that better preparation of parents for the transition to the community hospital may ease some of the stresses for both parents and staff. Our efforts to inform secondary care nurses about effective approaches in our ICN may reduce some of the discrepancies between the two settings, at least in non-medical care.

A final strategy in our own ICN is for the educational specialist to make herself available as a resource for nurses in concrete ways. Nurses appreciate suggestions about effective soothing techniques, but they also appreciate having someone to do it occasionally, when the baby is irritable and they have their hands full. Another area of frequent concern is interaction with parents. In some situations the educational specialist can serve as an effective communicative link between parents and nurses or other ICN staff.

SUMMARY OF COMPETENCIES NEEDED BY THE EDUCATIONAL SPECIALIST IN THE ICN

The educational specialist currently is identified by role and competencies rather than academic background. Most have extensive experience with handicapped infants and their parents. While many are special educators or early childhood educators, others have backgrounds in child development, psychology, occupational and physical therapy, nursing and other academic backgrounds.

The reason for the diversity of backgrounds is that appropriate academic and training programs are almost non-existent. Most educational specialists in medical settings gain requisite competencies from a self-made combination of applied experience, courses as available, training in specific procedures--such as use of the Brazelton Neonatal Behavioral Assessment Scale--and informal interchange with other health professionals.

There is a promising academic program at California State University in Los Angeles which might serve as a model for the development of other programs in the country. It is a Masters degree program which prepares people to be infant specialists. The program is open to those with degrees in education, psychology, nursing and related disciplines. All graduates attain the same set of core competencies. Among the experiences available to students in the program is a semester in the Intensive Care Nursery of a neighboring medical center. Another good program recently has been implemented by Wheelock College in Massachusetts.

Until programs such as these become more generally available, ICN educational specialists must continue to acquire their own expertise. Resources available within the HCEEP network, such as the EMI Curriculum from the University of Virginia (Wollens, Elder, & Hastings, 1979), have proved valuable for many new specialists. As the number and experiences of ICN projects in the network grow and expand, the resources will expand as well.

The technical and specialized knowledge needed by the ICN educational specialist seems overwhelming to the beginner. However, our experience has been that important preparation and expertise are already possessed by many people entering the field. A thorough basis in infant development, both normal and atypical, combined with an ability to work effectively with infants and parents, are a sufficient starting point.

What exactly are the new competencies needed by an educational specialist in the ICN? The following have proved essential in our project:

1. Specialized and up-to-date knowledge of neonatal and premature behavior, physiological organization, capacities and cues, as well as of current techniques for assessing these
2. Knowledge of the medical and developmental consequences of neonatal problems, particularly prematurity, but also other conditions such as intrauterine growth retardation, birth trauma, asphyxia and other complications
3. Understanding of medical procedures and technical aspects of the ICN, such as the monitoring systems, ventilation and feeding progressions
4. Awareness of indicators of distress and crisis in the neonate
5. Understanding of the roles and responsibilities of the different ICN staff
6. Understanding of the impact of the ICN experience on the parent and awareness of current ameliorative approaches
7. Finally, as for the ICN nurse, it helps to have four hands--two for all the equipment and two for the baby!

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HUMANIZING THE INTENSIVE CARE NURSERY*

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Over the last twenty years, the delivery of medical care to premature and sick infants in neonatal intensive care nurseries (ICNs) has undergone a technical transformation. Impressive medical achievements have changed the prognosis for critically ill infants, and consequently the survival rate for this population has increased considerably. However, the same technical advances have brought with them a host of new problems. The modern ICN environment is replete with negative stimuli for infants and their caregivers. The reconciliation of lifesaving and life-supporting medical technologies with a humane environment within ICNs is a major challenge to both medical personnel and educators in medical settings.

This chapter addresses the modern ICN environment from two perspectives. The first section describes the ICN environment and the stresses it places on each of three groups: infants, their parents and ICN nurses. The second section examines the role that developmental intervention can play in reducing those stresses. It takes a look at some current philosophies of developmental intervention and the need for developmental specialists, then offers a number of specific suggestions for assessment procedures, developmental intervention curricula, strategies for working with parents and nurses and strategies for educators to gain acceptance in the ICN.

THE ICN ENVIRONMENT

The ICN environment is inherently stressful. Those who receive treatment in the ICN are in crisis situations requiring emergency care, and that care, because of its highly technological nature, is not balanced to the emotional needs of patients, parents or staff. Each of these groups is subject to a variety of stressful factors. Some of them are unavoidable. Some can be reduced through modification of the environment and sensitive support by a developmental specialist. The basic stresses are discussed below.

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Factors in the ICN Which are Stressful to Infants

In order for normal human growth and development to take place in the first three years of life, certain basic needs must be met. These include the need to touch, move, taste and smell, to experience a variety of auditory and visual stimuli and, most importantly, the need for stable contact with a primary caregiver in a relationship that provides mutual gratification. In an ICN, however, infants are often deprived of these basic experiences due to the restrictions of their medical condition and treatment.

The premature and sick infant who is hospitalized for long periods of time during infancy is exposed to very different early environmental experiences than the full-term healthy infant. The full-term infant goes home after a few days in the hospital and, hopefully, has access to a consistent nurturing caregiver and an appropriate variety of sensory stimulation. The environment of the intensive care nursery, the first home of a sick or premature infant, may fail to provide patterned sensory experiences and opportunities for movement, touching and handling by a consistent caregiver. In fact, the infants who are cared for in ICNs are often subjected to a constant barrage of inappropriate stimuli. They are growing and developing in an abnormal environment, and, correspondingly, are at great risk for developmental delay. The following factors directly influence the stress levels of ICN infants.

Extreme Immaturity or Serious Illness. Infants treated in the ICNs are the youngest, the smallest and sickest of newborns. Most of the babies in an ICN are born premature (less than 38 weeks gestational age), and as many as half of these weigh less than 1,500 grams (less than 3 1/2 pounds). The premature infant's acute problems include respiratory distress, infection, neurologic problems, renal and nutritional difficulties. Infants admitted who are small for gestational age (SGA), caused by factors such as placental insufficiency or congenital viruses, have additional, unique problems related to liver functioning, hypoglycemia and other metabolic disturbances. Other babies are admitted to the ICN for surgical procedures such as repair of omphaloceles (intestines outside the abdominal wall which must be put back in), twisting of intestine or other blockages; and surgical repair can result in the removal of large amounts of intestine, causing short bowel syndrome. Whether infants are treated in the ICN for extreme immaturity or a serious illness, long-term hospitalization to meet the difficult nutritional needs of these infants usually follows. Other admissions to the ICN may include infants asphyxiated at birth, infants with congenital heart disease and infants with chromosomal or congenital anomalies. By the very nature of the ICN, acute-critical care demands extreme medical treatment for the patients.

Treatment Procedures. ICN infants are often placed under extreme physical restraints to facilitate medical treatment of their biological problems. Their limbs may be tied to prevent them from pulling out the intravenous tubes, others undergo curarization which paralyzes them in order to prevent their resisting the respirator. There are procedures which alter consciousness, such as administering anticonvulsants and sedatives, and techniques which invade body boundaries

such as tracheal intubation, umbilical catheters, chest tubes or hyper-alimentation. Other treatments bypass or abolish natural functions, such as gavage feedings, gastrostomy tubes in the stomach, mechanical respiration (which breathes for the baby) or eye patches placed on the eyes to protect against strong bilirubin lights. Moreover, the continual administering of laboratory tests and injections, changing monitor electrodes, taking blood gases and x-rays, all obviously involve excessive handling which causes discomfort for the infant.

Abnormal Physical Environment. The ICN environment is a cluttered one, with a hectic pace and constant heavy traffic. Babies are placed either on radiant warming tables open to undifferentiated stimuli or in isolettes with thick plastic walls which isolate them from human contact. Both babies and staff are exposed to intense fluorescent lighting for 24 hours a day without variation, which produces extreme fatigue.

There is a constant noise level in most units--a bizarre hum which is produced by the monitoring machines and alarm systems. Each baby may have as many as eight separate alarms and is attached to a ticking monitor which assesses heart rate and respiratory rate. One can imagine the noise in a typical 20-40 bed unit when an alarm system goes off, announcing that a baby's heart rate or respiratory rate is abnormal. (Parents quickly learn to respond to every sound around the bedside with understandable concern.) In the isolette the sound of incubator motors is constant and loud enough to obscure other environmental sounds. Many beds are near telephones or loudspeaker systems. Babies on open warming tables are vulnerable to the noise of the machinery, as well as the noise level of staff trying to talk above all the environmental noise. This becomes especially intense three times a day during a change in shift or during medical rounds, when four to eight doctors may be talking around the bedside. A recent study reported that sudden loud noises (such as the slamming of porthole doors to isolettes) caused agitation and crying in infants, followed by an increase in heart and respiratory rates (Long, Lucey, & Phillip, 1981).

Deviant Care Patterns. Babies in the ICN are touched and handled by a multitude of caregivers, including nurses, doctors, house staff, lab technicians, x-ray technicians, respiratory therapists, occupational and physical therapists, developmental specialists and the parents. Recently, one physician discovered that over a typical 4-month stay with three nurses a day, one baby may experience as many as 485 different changes in caregivers!

Several studies have found that the most frequent caregiving activity in the intensive care nursery is adverse handling related to carrying out technical medical procedures. Gottfried (1980) found in a study of the physical and social ecology of the ICN that infants were handled 16.7% of the time observed. Most of the handling was associated with medical or nursing care. Korones (1976) found that infants were disturbed an average of 132 times per 24 hours. Another study demonstrated that seventy-five percent of infants' hypoxemia was associated with handling (Long, Alistair, Phillip, & Lucey, 1980).

Factors in the ICN Which Place Stress on the Parent

Recent studies suggest that the conditions and events of birth greatly affect the development, strength and resilience of the caregiver-infant bond (Klaus & Kennell, 1976). Problems that are present in either the parent or the infant during this period have an impact and can jeopardize the future success of their relationship. Extreme parental distress during the neonatal period can result when the baby is premature, of low birth weight or ill. Although most parents of premature infants eventually develop successful relationships with their child, they usually must make tremendous compensatory adjustments to overcome the initial trauma of an untimely birth and its consequences. The parents of premature and sick neonates are faced with many losses including the limited early interactions so important to the development of a healthy parent-infant relationship. There are several factors which cause paralyzing worry and concern for parents.

The Survival Issue. The issue of whether their infant will survive is often paramount in the minds of parents. This is particularly true while the infant is acutely ill. Parents of premature infants are subject to strong conflicting feelings, particularly anxiety and guilt. They are usually shocked by the appearance of the infant and are confronted with feelings of uneasiness about the survival or lifelong outcome for their child. It has been observed that maternal anxiety varies inversely with the size of the baby, i.e., the smaller the baby, the greater the anxiety (Prugh, 1953). Feelings of guilt are often dominant after a premature birth, in spite of reassurances that no organic medical or obstetrical etiology can be found.

Loss of Expected Infant. An overwhelming psychological adjustment for the parent is dealing with the loss of the expected healthy infant before accepting the sick premature baby and his or her unique needs. However, there is often no time to adequately resolve the feelings of loss before parents must face the demanding job of beginning to invest emotionally in the new and unstable infant.

Separation of Infant and Parent. Immediately following birth the infant is whisked away to another ward or to another hospital, perhaps hundreds of miles away. Separation has a profound effect on parenting. The literature on this subject expresses the importance of having the mother see her premature baby as soon as possible, which is often not possible if the baby has been transported to another ICN (Klaus & Kennel, 1976).

Loss of Control. The issue of loss of control is a painful one. Many parents state that they feel their baby belongs to the hospital, the nurses and the doctors. They feel that the baby is not their own and that they have no voice in decisions that are made about the infant's health care. As one mother stated at discharge, "I feel as if I am taking home my adopted baby."

Effects of the ICN Environment on Parents. The parents' first visit to the intensive care nursery to see their baby is stressful for many reasons. Parents report that they are overpowered by the sights and sounds of technological medical equipment, and some say they come close to fainting. One parent told us following her first visit, "All I could focus on was his chest going up and down and how tiny he was." The anxiety level is so high that it interferes with accurately perceiving the full reality of the situation (Hawkins-Walsh, 1980). Perception may be impaired to the point where a parent will focus on details such as the shaved head or the heaving chest and will not see the whole child. Some parents respond by keeping a safe distance from the isolette at first and upon each visit may stand a little closer until it feels "safe" to reach in and touch the baby.

Factors in the ICN which Place Stress on the Nurses

There is a paucity of information about the stresses affecting nurses in the ICN as professionals and caregivers. Yet nurses are in a very vulnerable position. They spend more time at the bedside than any other professional in watching and responding to the baby's every need. There are numerous sources of anxiety and stress in the ICN setting for the nurse.

Emotional Stresses. Nurses report much inner turmoil and various levels of self-involvement in caring for acutely ill infants. They express feelings of depression, anger, guilt and a desire to withdraw during the course of a baby's illness. Facing the frequent conflicts of life and death invariably causes grief and sorrow. Particularly stressful situations include being involved with a baby whose respirator must be discontinued, feeling attached to a baby they must watch die, or being ordered to maintain life supports for babies that the nurses feel are already dead.

Stresses Related to the Nurse-Doctor Relationship. The role of nurses often vacillates between having their observations ignored by doctors and being overloaded with responsibilities that doctors should handle. Nurses may be left, for example, with the duty of telling parents information that should come from the doctor, such as the circumstances of an infant's death. There are also situations in which doctors step into nursing jurisdictions, producing conflicts.

Stresses Related to Dealing with Parental Responses. Dealing constantly with overburdened parents is a strain. Parents have a great number of questions about treatment and procedures; some demand explanations for everything the nurse does. Mothers need to review the labor and delivery experience to work out their own fears and guilt, and they need an understanding nurse to listen. Nurses may also find themselves dealing with parental anger which, although it reflects the parents' healthy attempt to cope with an enormously depressing event, may be directed at them.

Stresses Related to Working in the ICN Environment. Nurses report that there are many fatiguing factors in the ICN itself, such as the constant noise level, daily exposure to catastrophe, listening every minute for monitor alarms, being under intensive lighting for eight hours and working in a cramped space. Nurses continually view extremely tiny, scrawny infants, hooked up to machinery with tubes emanating from many parts of their bodies, or deformed infants, the result of genetic mishaps. As part of the daily routine the nurse may have to support the parents of a terminal infant dying of heart failure or change the dressing of an infant's gangrenous limbs.

Stresses Related to the Work and Its Demands. Nurses are required to perform excessive repetitive tasks as part of the ongoing routine in an intensive care unit. A typical hour includes checking intravenous (IV) levels and vital signs, checking O₂ concentrations, suctioning, checking blood gases, measuring input and output from urination or nasal gastric tubes, and other lab work.

After completion of all the detail work, every task must be charted. When the work on one patient is completed the next is begun, unless the nurse has already been interrupted by an alarming monitor or an emergency. The workload is relentless. Many tasks, which are usually performed in other units by nurses' aides, must be executed by staff nurses in the ICN due to their special nature. Even changing a patient's bed in the ICN requires specialized skill in moving the tiny infant, who must be kept warm at all times, while maintaining attachment to respirator tubes, hyperalimentation lines and chest tubes.

DEVELOPMENTAL INTERVENTION

A common strategy for reducing the negative effects associated with prematurity has been the use of intervention programs that are designed to increase the infant's sensory stimulation. These programs are based on the assumption that hospitalized infants are sensorily deprived. Some researchers have seen this deprivation in terms of the loss of rich in utero experiences (Barnard, 1972; Korner, et al., 1975; Neal, 1968), while others have attempted to approximate the sensory experiences of full-term, normal neonates (Barret & Miller, 1973; Miranda, 1976). The amount and kind of recommended stimulation varies.

In a review of several studies where premature infants received early stimulation, Masi (1979) concluded that although there is a wide variety of intervention methodologies and results, most of the studies report some benefit to experimental infants involved in early stimulation. Specific benefits were noted in weight gain and improved behaviors such as visual and auditory responsiveness, development of motor skills and less crying. Studies using multi-modalities of stimulation offered daily, showed improved functioning on tests of visual and auditory responsiveness.

Other researchers suggest that premature infants may suffer from an inappropriate pattern of stimuli in the ICN rather than from an inadequate

amount of stimulation (Lawson, Daum, & Turkewitz, 1977). Als, Lester and Brazelton (1979) and Gorski, Davidson and Brazelton (1979) propose the idea of a sensory overload in the ICN environment and encourage a sensitive look at each infant's behavioral responses to environmental events. Their goal is to assist the infants, through an understanding of their sensory capacities, to use appropriate positive stimuli to organize themselves. While realizing that most of a sick infant's energies are thrust into survival efforts, these researchers view the infant as an active participant, reacting to every aspect of medical care and environmental conditions. Apnea, bradycardia, sudden changes in heart rate or respiration, even cardiac arrest, are viewed as possible autonomic responses to the ICN environment and activity (Gorski, et al., 1979).

These studies indicate that preterm infants provide definite behavioral cues to their neuro-physiological stability, disorganization or distress. They give cues through changes in color, tone, facial expression and fluctuations in respirations and heart rate prior to physiologic stress (Gorski, 1980). When stimulation or caregiving procedures are inappropriate or overstress an infant, marked signs of autonomic lability such as fluctuation in heart rate, respiration or tone and color changes can be observed. On the other hand, when caregiving procedures are based on a sensitive observation and reading of these cues and altered accordingly, improvements in recovery will result (Gorski, in press). Such alterations might include offering rest periods between medical procedures, turning an infant with the limbs contained or offering eye contact and smiling only if an infant is responsive.

It is apparent from a review of the literature that we need additional studies which take into account the kind of stimulation these babies are constantly receiving and coping with in the ICN. We also need studies that assess the individual threshold of each particular infant for handling stimulation, to assess infants' attention levels, their coping mechanisms and the considerable individual differences in processing capabilities among preterm infants.

The Need for the Developmental Specialist

While there may be intervention programs in the ICN which seek to provide infants with supplemental stimulation, this stimulation is often given without an awareness of all the stressful factors impinging on the infant. For example, therapists are sent to the unit to stroke or touch the baby or offer a variety of visual, auditory and/or vestibular stimulation; but there is little effort to individualize the approach or to weave care recommendations into the daily nursing plan for that infant. In many instances, all babies in an ICN receive the same mode of stimulation applied in a similar manner. Often there is no effort to involve parents or nurses, and thus the program lasts as long as the therapist is at the bedside and has no developmental continuity. In many instances, interventions are based on traditional strategies for ameliorating developmental delay in older infants with no regard for the specific needs of the premature infant.

Nurses are usually the first to recognize the need for some response to infants' subtle behavioral cues. They note continually what an infant's tolerance or capacity for processing stimulation might be, and the infant's range of responses. During their eight-hour shift of observing and handling, they are often acutely aware of sleepy unresponsiveness in the behavior pattern or excessive irritability. Yet nurses do not always have the ability to communicate their observations in a meaningful, efficacious manner. Their observations are not being utilized to provide optimal care for the infant.

Parents, too, need an informative support person. They can feel helpless and inadequate as they visit and try to make some sense from the medical information--often the only help they are given in understanding their infant. Many are confused and frustrated when the baby responds with gaze aversion instead of arousal or alerting to the parents' attempts to interact. The baby appears so fragile; they cannot imagine themselves caring for such a tiny, weak being.

An infant developmental specialist is in a unique position to respond to the needs of infants, nurses and parents in the ICN and to provide developmentally coordinated infant care. Armed with a knowledge of prematurity and its related illnesses, of normal and atypical infant development, the infant developmental specialist can intervene in the ICN to facilitate the development of these high-risk infants. The specialist can introduce activities to reduce the negative aspects of the ICN experience for the infant and can provide support and education to the parents and staff about infant developmental needs.

The Developmental Assessment

The first step in the process of intervention for the infant in the ICN is the completion of a developmental assessment. This is initiated after the infant has passed the acutely-ill phase and is medically stable. The assessment by the developmental specialist includes three major components. Each is discussed below.

Observation of Infant Response to Handling by the Nurse. Repeated 5-10 minute observations are completed by the developmental specialist in which state, physiological response (heart rate, respiratory rate, color changes, startles, tremors) and activity level are recorded every 30 seconds during a routine caregiving procedure (i.e., a diaper change by the nurse). This observation provides valuable information as to how the infants are reacting to every aspect of ICN care. Do the infants show increased respirations every time they are turned over from prone to supine? Do they turn pale or blue when vital signs are taken?

Information from this part of the assessment can be used to formulate alternatives and recommendations in caregiving procedures by the nurses. For example, one infant demonstrated an increased respiratory rate after a blood gas was taken. Because the infant had stopped crying, the nurse assumed he was no longer stressed and ceased her soothing. However, the specialist noted that even

though crying had stopped, the respirations continued to increase for several minutes longer. The developmental specialist was able to point this out to the nurse and recommend that a few more minutes of comforting might be necessary to prevent stress.

This technique of observing and sharing observations enables the specialist to make some very specific, appropriate suggestions regarding various aspects of caregiving. It also becomes a teaching tool for nurses who are able to see instantly how a caregiving technique could be altered to reduce the infant's stress.

Developmental Assessment of the Infant. The Assessment of Preterm Infants' Behavior (APIB), a new assessment procedure developed by Heidelise Als (1980) is an instrument used to document the developing behavioral capacities and organization of premature infants from the stage when they are stable enough to be handled in room air without medical aids to the stage when their attention system is self-regulated. The APIB systematically offers increasingly demanding environmental inputs to the preterm infant and rates infant response. From clinical use of this assessment procedure, one can document infants' current level of organization, their threshold of disorganization and areas of poor functioning and their strategies of self-regulation. Moreover, the degree and kind of environmental support necessary to promote optimal functioning can be identified as the infant is moved through the maneuvers with a consistent focus on the five subsystems: psychological, motor, state, attentional-interactive, and regulatory. The APIB examination takes 30 minutes to administer, and the scoring takes approximately 1 1/2 - 2 hours. Training in the scoring and administration of the APIB requires reliability in the administration and scoring of the Brazelton Neonatal Behavioral Assessment Scale plus additional extensive training and experience in handling preterm infants in the intensive care nursery.

Nursing Assessment and Interview. A description of the infant's behavior by a nurse who has taken care of the baby for several shifts is very useful in planning appropriate modifications and interventions. The nurse may be interviewed by the specialist and asked to describe the overall responses of the baby to caregiving. Factors such as amount of crying, length of alert periods and amount of stress during handling give invaluable clues to the specialist as to how to approach the infant's world, the timing of therapy sessions and appropriate recommendations for the nurse regarding caregiving practices.

The Individualized Development Plan

A compilation of all the assessment information gives the developmental specialist knowledge of the baby's routine caregiving experiences and range of behavioral responses to those experiences. (It is important to note that not all responses are behavioral and immediately observable. Some are expressed on a physiological level such as sudden limpness of tone or color changes from pale to blue.) From this information an appropriate Individualized Developmental Plan of

caregiving recommendations can be devised, along with some activities for promoting interactional abilities between caregivers and infants.

The content of these recommendations would consist, first, of appropriate environmental modifications which would minimize, modify or augment the environmental stimuli around the baby. As the baby begins to recover and alert states begin to emerge, very simple, well-modulated face-to-face interactions are suggested for baby and caregiver. Several questions are considered as the specialist begins to plan the interventions: When does this baby sustain any periods of alertness? When the parent visits? After the bath? At the feedings? How much effort does it take this child to arouse to an alert state? How long can the alert state be sustained? What is the quality of the alertness? Is the baby stressed by being alert?

A developmental plan itemizing 8-10 specific activities and methods can be created based on the information learned in the developmental assessment, observation and nursing interview. From this "master plan" which covers the next month of the infant's stay, two or three activities are chosen weekly and posted at the bedside for medical staff and parents to review.

The infant is visited daily at an appropriate time agreed upon by the nurse or parent and developmental specialist. A review of the infant's responses and activity level is discussed, and feedback is elicited from the parent and nurse as to the effectiveness of activities recommended the day before. The developmental specialist assesses the infant's environment and makes suggestions regarding reduction of any excessive lighting or unnecessary noise. (Usually, with regular changes in staff, suggestions have to be repeated frequently.) If the infant is in an appropriate state, developmental activities from the plan are modeled to the caregivers, who are then encouraged to practice these activities, providing they are not too taxing for the infant. Throughout the handling, behavioral and physiological changes are pointed out to educate the caregiver regarding the infant's ability to handle stimulation.

It should be noted that nurses are not always available to work with the specialist due to the demands of other infants. It is important for the specialist to be supportive and not overburden the nurse. Providing the nurse with one clear suggestion per day is the most effective way to ensure cooperation and follow-through.

After each daily visit, if specific activities are offered, the developmental specialist makes note of the infant's state and responses. These notes are reviewed at the end of each week; progress is summarized and new activities suggested for the following week. Developmental goals and methods used should be regularly updated and reviewed with parents and staff. In planning developmental recommendations, the following four principles should be taken into account:

1. Interventions Must be Consistent with the ICN Environment and Not Interfere with Medical Treatment. The basic reality of the ICN environment cannot be altered to make it a totally appropriate developmental experience for infants. However, various aspects of this environment can be modified as they affect infant development, i.e., reduction of noise, light and traffic around the baby.

2. Interventions Must be Consistent with the Infant's Gestational Age.

Preterm babies--those who are born prematurely and who are 40 weeks or less in age--often exhibit disorganized states and should be offered interventions that involve a reduction in stimuli. Modifications of the environment or alterations in handling during caregiving and medical procedures are recommended, such as covering the isolette to reduce the strong fluorescent light or sensitizing staff not to place the isolette under a telephone or loudspeaker microphone. As these infants begin to become more organized and responsive, brief periods of sensitively timed, appropriate visual and auditory activities are offered.

3. Interventions Must be Timed to the Infant's Cycles--Not Given at Set Times. In order to be effective, the specialist must be regularly available to the parents, nurses and infants throughout the entire day and to the night shifts. The traditional one-half hour therapy session, even though convenient for the therapist's schedule, may not be appropriate for the infant, nurse or parent. In order to catch the brief alert period or to assist the nurse with an irritable infant, the developmental specialist must be present to be called on when needed. In addition, activities should be emphasized which are woven into the daily caregiving routines and not given at set times. The primary caregivers, nurses and parents, are offered a demonstration of each activity and shown how to take advantage of the infant's alert states to offer interaction. Staff and parents are sensitized to the physiological changes that can occur as a result of handling. One nurse was astonished when it was shown that the increase in mild apneic (non-breathing) spells was related to the technique she used to turn the baby over. When she rotated the baby slowly and gently, with the limbs contained, the mild apnea ceased.

4. Interventions Must Be Appropriate to the Changing Needs of Each Infant and Sensitive to that Infant's Cues. The responsiveness of a sick or stressed infant is often expressed on a physiological rather than an interactive level (Gorski, in press); excessive handling or ill-timed interventions can stress an infant physiologically. Observation of the subtle cues in the baby's physical signs and behavioral repertoire--such as changes in color, fluctuations in heart rate or respirations, presence of startles or tremors, changes in muscle tone, or gaze aversion--is essential to plan appropriate developmental caregiving recommendations. The specialist must be ready daily to evaluate the responsiveness of each infant and must be flexible in the recommendations offered. For example, a 36-week gestational age infant in hood oxygen may be able to sustain a one-minute period of alertness showing brief attention to a face and may actually track the face 30 degrees horizontally. The next day the infant may not arouse to more than a drowsy sleepy state all day and be unable to focus or follow a visual stimulus.

Recommendations should be suggested to nurses and parents with special attention paid to infant states. A soothing routine of swaddling, prone positioning and offering a pacifier may be suggested for the excessively irritable infant; a short 30-second experience with a visual stimulus of the face alone may be

suggested for the briefly alert infant; and simply encouraging a parent to hold the infant close may be suggested for the still sleepy baby who cannot yet muster an alert state.

Developmental Curriculum

The developmental recommendations or curriculum for the preterm and postterm infant include several environmental modifications as well as developmental activities to promote interaction between infant and caregiver. No activity is suggested until each infant has been evaluated to determine his or her threshold for stimulation and range of responses. Of course, the infants are continually observed to note how they are responding on all levels. At any time if any activity disturbs an infant, it is stopped. The preterm and postterm curriculum are outlined below.

Preterm Curriculum:

1. ENVIRONMENTAL RECOMMENDATIONS:

- a. To reduce light:
 - Cover isolette with blanket.
 - Cover open cribs for naps.
 - Shield infant's eyes when held.
 - Turn off overhead lights whenever possible and use individual lights at each bedside.
- b. To reduce noise:
 - Avoid playing radios in units.
 - Avoid placing isolettes, warming tables, cribs, etc. near telephones or microphones.
 - Talk over loud speaker only when absolutely necessary.
 - Avoid tearing open paper-wrapped syringes or other medical equipment near infant.
 - Avoid carrying on conversation or having medical rounds over the bedside.
 - Separate convalescing infants from acutely-ill infants so that convalescing infants will be less disturbed by the noise level of monitors.

2. HANDLING RECOMMENDATIONS:

- a. Handle slowly and gently
- b. Offer one sensory modality at a time:
 - Present face, then voice, then touch, noting infant's responses to each mode.

- Learn when to stop and when to encourage alertness with each infant.
- Remember that each infant's threshold is different.
- c. Space out the handling:
 - Give 15 minute breaks between caregiving tasks and medical procedures. Sometimes after a bath or feeding is the worst time to interact with babies because they are tired and may be stressed.
 - Let baby recover.
- d. Physical restraints:
 - Use soft velcro wraps with elastic ties.
 - Position baby in sidelying with hands together at midline.
 - Wraps should be placed around the wrists with the ties fastened to bedding giving baby some freedom of movement.
 - If possible, position babies so they can bring their hands to their mouth to suck on their fingers, enabling them to soothe themselves.
- e. Soothing:
 - Consistency in caregiving and handling is the key here.
 - If the baby cannot be picked up, have the primary care nurse swaddle baby's body with her hands. Also helpful is to position the baby in a prone position and pat gently on the back.
 - Touch and suck seem to be very effective modes to offer.
 - It is imperative to watch baby's cues (heart rate, respirations, etc.). Many babies need to be left alone for long periods of 2-4 hours.
 - Reduce handling to a minimum.

3. RECOMMENDATIONS TO FACILITATE FEEDING AND INTERACTION:

- a. To Facilitate Suck:
 - While holding infant, offer wet finger slowly inserting to stroke roof of mouth with fingertip. If this stresses the infant, stop. If it doesn't, a minute or two of this practice between feedings is excellent. For some babies it cannot be done prior to feeding because it tires them for the feeding. Abnormalities in

suck or swallowing should be referred to an occupational therapist, physical therapist, or the infant educator for evaluation. Also, offer a pacifier during gavage feedings.

b. Visual Activity:

-If the baby is showing alert states, present face eight inches from baby's eyes. If baby attends, encourage tracking first horizontally 30° - 60°, then vertically and circularly. Voice may be added after attention to face is achieved. Do not push to elicit an alert state. If babies show they can achieve an alert state, and orient to visual or auditory stimuli, respond to them, but always be sensitive as to when to stop to avoid overtiring. A bright red yarn ball or paper party plate can be placed in the isolette. Avoid overcrowding by placing one object at a time in the infant's visual field. If it causes stress, remove.

c. Auditory Activity:

-If baby is drowsy or alert, talking slowly at each ear may elicit increased alertness and arousal. Quieting to voice may be seen with increased respirations. Many babies even orient to the voice by turning their head towards the voice and beginning to search with eyes. This may be attempted at each side. If there is no response or change of state to the voice, it may be tried again later.

d. Tactile Stimulation:

-Many babies benefit from gentle stroking, head to toe, in downward motion with lotion or textured mitt. Again, this should not be carried out if it stresses the infant. It is not appropriate for every infant. Some can only tolerate 5 seconds while others can take up to 3 minutes or longer.

Postterm Curriculum

A variety of infant stimulation curriculum guides are available (HELP, 1979; Home, 1973; Meier & Molone, 1979) and can be used as a basis for recommending developmental activities for postterm infants in the ICN. However, modifications of available curriculum will be necessary. When stimulation is offered to the infant in an ICN setting, it must be adapted to the constraints of the medical

care, such as IVs or deep skin tubulation. Also, therapeutic interventions must take into account any defensive reactions or aberrant behaviors of the infant and modify the intervention for these factors. For example, some infants do not attend well, may avoid eye contact, show irritable reactions to handling or withdraw from interactions. We must respect these defensive reactions and proceed only when the infant is ready to respond. Furthermore, infants learn best when they themselves can make something happen. Because infants in the ICN are restricted by respirators, tubes, etc., and are in the limited space of the crib, there is very little opportunity to act on the environment. To counteract the passivity which is encouraged by the setting, interventions must afford every opportunity for the infant to interact meaningfully with objects and people whenever he/she is ready.

The following areas should be included in a postterm curriculum:

Prehension Skills. One of the first activities noted in ICN infants is batting and/or swinging at objects. Infants are reluctant to abandon this activity since it is one area in which they can make something happen. It is important to give the infants opportunities to continue swinging while introducing other activities to encourage grasping and reaching.

Visual Skills. Hospitalized infants are either assailed by a plethora of stimuli or offered too little. It is important to offer stimulation and also to screen out the background and excessive lighting. Help the infant to focus on a specific visual stimulus, perhaps in a special quiet room adjacent to the nursery. Covering the cribs at sleep time helps to avoid excessive light exposure and gives the infant a sense of change. A bright patterned object can be placed at eye level in the isolette for the alert infant. Rotate position and vary the object daily.

Auditory Skills. Bells and rattles can be irritating to very young premature infants. However as infants mature, they are able to begin to orient to various sounds. Music and voice stimulation are more easily tolerated, especially if the infants are in the isolette where they are isolated from all sounds except the vibrations of the incubator. Parents are always encouraged to talk or sing to infants even though the baby cannot respond.

Tactile Skills. Recommendations will be made for gently stroking infants with baby lotion or oil during caretaking routines, gently rubbing with a mitt made of soft materials such as satin or velvet for tactile experiences after the bath, or to prolong the bath so that the infants can explore the sensations of the water on their body. Caregivers are encouraged to cuddle, hold and rock as well as walk with the baby.

Motor Skills. Infants with head lag can be worked with to develop head control by holding at the caretaker's shoulder, positioning on the caretaker's chest and by rolling and trunk control exercises.

Social and Language Skills. Infants who are beginning to be responsive often attract passersby who engage in sporadic, fleeting encounters with them, leaving them deprived of meaningful contact. To counteract this tendency, care should be taken to give the infant exposure to only a few consistent caretakers on a daily basis, where face-to-face interaction is encouraged. During feeding and caregiving activities and face-to-face interactions, gentle talking and imitating the sounds of the infant are encouraged to give the infants feedback for their responses.

Intervention Strategies in the ICN with Families

A primary goal of the developmental specialist is to ameliorate stress in the ICN for families. This requires establishing rapport and trust. The relationship is a unique one, in that the specialist is not viewed as medical staff and has an interest in encouraging parenting skills. The specialist must collaborate with the family during this extremely stressful time, viewing them as potentially successful in adjusting and compensating for the burdensome event of having a sick baby. In addition, the specialist must recognize individual levels of responsiveness in parents as they cope with the ICN and begin to interact with their sick or premature infant. It is important to consider the parents' capacity and willingness to spend time in the ICN, taking into account distance from home, job responsibilities, other siblings or family needs and the parents' emotional state.

Strategies to Facilitate Attachment. Many parents view the infant at first as a chemical entity or medical problem, described in terms of current weight gain, oxygen levels or the status of lung disease. After the acute concerns regarding survival have passed, fears as to the quality of life persist in parents' minds. A process of finally coming to identify with their child begins as the infant gains weight and is no longer attached to tubes and monitors. Throughout this process, the developmental specialist can remind parents that their infant is a human being with specific preferences who can hear and feel their presence in spite of the inability to respond. (This lack of response can lead to feelings of helplessness and inadequacy in parents when caring for these infants. It is agonizing to attempt to nurture and interact with an infant who may squirm away while being held or avoid the parent's gaze.)

The process of educating parents in developmental concepts begins by helping them overcome any resistance experienced around handling an underdeveloped, fragile infant attached to monitors and tubes. Regular meetings at the bedside provide opportunities to point out the infant's responses to caregiving procedures. The specialist can also begin to help the nurse involve parents in as many of the caregiving tasks as possible, such as giving the bath or holding the infant during gavage feeding. Parents are encouraged to make those first steps to view the baby as a person. This involves getting close to the isolette, touching, holding and talking to the infant.

It is most important to show parents how to observe the infant's behavior. The specialist contacts parents to share the developmental assessment, discuss the appropriateness of the developmental goals outlined for the infant and to elicit their comments and suggestions. It may be necessary to interpret the infant's responses. By pointing out the disorganized movement, the fact that turning quickly may result in irritability and that swaddling can reduce irritability, parents can be shown that their baby's behavior is typical for a premature or sick infant and that it will improve. Many times, when parents realize that they are not causing the infant's stresses, they can begin to understand and help their child.

Another job of the specialist may be simply to listen to parents' many concerns with a trained ear in order to learn the greatest source of fear and anxiety; many parents need to unload the intense feelings associated with a frightful delivery and the events which followed. One method of support that consistently relieves anxiety is to prepare the parent for each step in the progression of recovery by giving them hallmarks around which to make plans, for example, preparing them for the first feeding, for the transition from isolette to crib or for transition to a secondary hospital.

Strategies to Reduce Parental Stress Factors in the ICN Environment. Perhaps one of the most interfering variables for families is the lack of privacy in a large ICN. It is difficult to express sadness, relief or intense anxiety in a room full of 50-75 people. Providing opportunities for privacy by placing screens around the bedside or designating a small room adjacent to the nursery as a breastfeeding room can facilitate time alone for parents and infants who are able to be moved. Rocking chairs at the bedside are essential for parents to provide a comfortable holding and rocking experience.

Visiting hours should be around the clock, even during medical rounds. Siblings should be allowed to visit at least once a week, possibly on Sundays. Even though the number of visitors at the bedside needs to be limited, parents should be able to bring with them whomever they like.

Strategies to Facilitate Discharge Planning. Parents have the greatest need for support during the time immediately following discharge. This is a time when the support of the ICN staff is no longer available. It is not uncommon for questions and anxiety to arise regarding various aspects of caregiving, such as sleeping patterns, reducing irritability, and feeding difficulties. Follow-up during the first month or two by a trained specialist from the ICN who is familiar with the family can provide the missing link of support. This role necessitates that the specialist be knowledgeable in the medical problems associated with prematurity and neonatal illness, parent-infant interaction and the infant's developmental needs.

Some infants are transferred from tertiary care nurseries to secondary care nurseries in community hospitals when their condition no longer warrants the special medical therapies available in the ICN. Yet these infants are still too immature or underweight to be cared for adequately at home. Many infants spend weeks to months in these community nurseries. To insure continued progress in

developmental activity and in parent-infant interaction, the developmental specialist must carry on the relationship with the family in these secondary units.

Prior permission must be obtained for the developmental specialist to visit other hospital nurseries. Contacting the medical director of the unit to explain the unique aspects of this service is recommended. The physician must also be contacted who is in charge of the infant's care. Once permission is obtained, the specialist should keep that physician appraised of the infant's progress.

When an infant is ready for transfer to a secondary nursery, further planning begins. Parents are usually very concerned about the transfer because of the recent critical nature of the infant's illness. They may often express fear over the move, viewing continued intensive care observation as more important than having the infant close to home. Early discussion to secure the parents' permission and explain the reason and merits of the transfer is essential. Parents should also be prepared for the differences in routines and approaches they will find in the secondary nursery (Abbey, et al., 1978).

During the infant's stay in a secondary hospital, the developmental specialist makes at least weekly visits to the nursery. These visits are to assess the infant, meet with the family, review with the nursing staff the progress of the infant and continue to carry out various developmental activities.

Intervention Strategies in the ICN for Nurses

Nurses play an essential role in carrying out developmental activities because they are the consistent caregivers and the primary source of human contact for the infant. They provide much of the infants' touch experience and handling. Their voice and face are major sources of auditory and visual stimuli for these babies. The educational specialist can educate nurses about their impact on the baby's development and can also help reduce some of the nurses' stresses in the ICN. The following are suggestions for assisting and building relationships with nursing staff.

Relieving the Nurse. Perhaps the most effective way the developmental specialist can reduce stress in the ICN for the nurses is to offer relief for them from some of the caregiving needs of the baby. This should only be done when advisable and acceptable to the nurse. The developmental specialist can meet with an anxious parent, feed a hungry infant or soothe a very irritable infant.

Support for Primary Care Nurses. Some hospitals have a policy of assigning one nurse as the primary and consistent caregiver for a particular baby. This reduces the number of caregivers and insures continuity of care. This policy may be best for the baby in reducing irritability, promoting feeding behavior and providing consistency in caregiving. It is beneficial for parents in that they need only develop rapport with a few nurses who are familiar with their baby's needs. On the other hand, it may not always be best for the nurse. Many nurses complain they become "burned out" and lose their acute nursing skills by caring for long-term convalescing infants. Moreover, nurses often develop attachments to babies whom they surely will never be able to keep.

Solutions to this problem might include developing a nurse support system or assigning nurses to each baby for two weeks. One method of providing support can be a low key "bull session" for the ICN nurses participating in primary care, offered by a psychologist with skills in fostering parent-infant interaction and an understanding of the problems in interaction for parents of sick infants. Nurses can view the psychologist as their resource for venting feelings about particularly difficult situations, such as the following:

- One nurse had three of "her babies" in succession become partially sighted from retrolental fibroplasia (RLF--loss of vision due to ventilation therapy). She was afraid to take on another primary care assignment for fear this would happen again.
- A group of 4 nurses had taken on primary care for an infant whose mother was close to dying. There were intense feelings among the nurses as they cared for a baby they viewed as "motherless".

In their bimonthly discussion with the psychologist, feelings centering around sensitive issues such as these are explored and relieved. The attendance and make-up of each session varies depending on the nurses' need and schedule.

Involving the Nurse in the Assessment Procedure. The developmental specialist should seek to establish rapport with ICN nurses and to become familiar with their motivation, their daily routine and the nature of their interactions with infants. The nurse's observation of the infant, solicited through a questionnaire and interview, assist the specialist in planning appropriate developmental activities for the infant. This also keeps the specialist informed concerning the effects of certain caregiving practices on infant behavior.

Educating the Nurse in the Developmental Plan. The specialist should seek to develop a partnership with the nurse and parent in which all share information regarding the baby's progress. A primary objective is to enlist the efforts of the nurse toward modifying the environment of the ICN for the infant's benefit. One or two developmental activities from the weekly goal sheet can be modeled for the nurse daily. In all instances the nurse should be encouraged to observe the subtle behavioral cues of the infant during caregiving. This may include writing brief notes on any significant progress in the infant's responses to caregiving procedures and toward the developmental activities offered or coming to weekly developmental "rounds" to share their experiences with the baby. (Realistically, nurses can make these meetings only when there is flexibility in the agenda--so that nurses can present their baby for 5 minutes as soon as they arrive--and meetings must be held close to the nursery.)

Training Courses. Nurses should be educated in infant development, parent-infant interaction and the developmental needs of premature and sick neonates. The developmental specialist at the author's project, the ICN Interact Project, at the Child Development Center in Oakland, California offers two 4-hour courses giving continuing education credits. One class, "Developmental Issues in the ICN",

covers information related to basic infant needs, the ICN environment and its effect on development and the jeopardized parent-infant attachment. Conducting a course for nurses provides the educator with an excellent opportunity to explain the risks of long-term illness, prematurity and hospitalization on the development of these infants. The rationale for a developmental program in the ICN is explained, along with demonstrations of specific activities nurses can carry out with infants and parents and methods for assessing developmental needs.

A second course, "The Normal Newborn", is taught in a normal newborn nursery where newborn behavior and the amazing interactive capacities of the healthy newborn can be demonstrated. Nurses working in ICNs often have little opportunity to view normal newborns and thus may have low expectations of infant behavior.

The Nurse Liaison. A clinical nurse specialist whose areas of responsibility and interest include discharge planning, parent-infant interaction, infant development and the ecology of the ICN is a natural consultant for the developmental educator. This connection can improve the educator's relationship with the nursing staff and offset the "expert role" approach that is so threatening to nurses. A nurse is necessary to advise the educator on the practicality of developmental recommendations and how to approach and share information with nurses. The nurse liaison is an excellent way to bridge the gap between the educational professional and the medical professional.

Follow-Up Communication to ICN and Secondary Nurseries. To create a sense of completion of care for the nursing staff at both the tertiary regional center and the secondary care nursery, it is important to communicate information about the infants cared for while they were critically ill. A follow-up program allows the perfect opportunity to share the later progress of babies with the nursing staff. All shifts of ICN nurses want to know the progress of "their babies." An easy method of communication is a picture taken during the home visit and a brief written summary of the child's and family's progress which is then posted in a central location--usually the nurses' lounge--for several days. This simple form of communication affords nurses the opportunity to see the infants become growing human beings and gives them the encouragement to continue in a very stressful and demanding nursing role.

Acceptance Strategies for the Developmental Specialist

The developmental specialist is a newcomer to the intensive care nursery. In order to maximize the effectiveness of this new role in the ICN and gain acceptance in the medical arena, the following four strategies are offered as general guides:

1. Elicit the input of nurses about their needs, their ideas and their concerns about the developmental needs of babies. Avoid playing the expert role and the "we're going to make it better" attitude. An example may serve to illustrate this point. The staff in one unit sought to know more about the needs and concerns of parents by having an open forum with nurses in their unit who had themselves been parents of premature babies. A brainstorming session was arranged, resulting in a heightened sensitivity to the emotional stresses these nurses underwent as parents. A superb list of recommendations aimed at reducing stresses for parents in the ICN was the outcome, and a new consciousness of parent's needs was developed on the part of medical staff.
2. Modify your ideas as you accept nurses' recommendations and formulate your approach to meet their needs. At this point, you should have their permission to make changes. If you do not have nursing support, you must step back and re-examine the approach used. A developmental program in the ICN requires nursing support to be effective.
3. Explain the goals of your program in a training course or special seminar. An understanding of the risks faced by infants in the ICN in terms of their development is essential in order for nurses to understand why developmental intervention is so valuable.
4. Give feedback to the neonatologists and nurses regarding the effects of activities for parents and infants. Interdisciplinary rounds--a weekly meeting with the neonatologists and all supporting disciplines in the ICN to review new admissions and discharges and to update the staff on each baby's condition--affords the educator an excellent forum for sharing information with the medical staff about developmental concerns for the baby. Here the developmental specialist can participate as a member of the medical team with physicians, nurses, social workers and therapists regarding parent and infant needs.

SUMMARY

There are numerous environmental, treatment and separation factors in the ICN which inhibit and distort the process of normal infant development, jeopardize parent-infant attachments and place stress on nurse-infant, nurse-parent relationships. Attempts to humanize the ICN environment and promote the development of premature and ill infants can be successful. They can minimize the negative aspects of this experience for infants, parents and nurses by modifying some of the aspects of the environment and by augmenting, where and when appropriate, the infant's sensory experience.

However, it is essential, as educators in a medical setting, to realize that there is a time to intervene and a time not to intervene. It is also essential that the developmental specialist acquire a great deal of knowledge about infants' physical needs and condition, their behavioral capacity in the ICN environment and the factors which interfere with meaningful human interactions in order to plan appropriate interventions.

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DEVELOPMENTAL CONSULTATION: THE ROLE OF THE PARENT/INFANT EDUCATOR IN A HOSPITAL/COMMUNITY COORDINATED PROGRAM FOR HIGH-RISK PREMATURE INFANTS

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The practice of early intervention has evolved very differently in different settings; depending on such factors as the size and technical capabilities of the institution, staff expertise, program philosophy and population served. This paper describes an intervention model that is highly flexible and capable of adapting to the needs of a variety of hospital and community programs. It is being developed by Project WELCOME in Boston, Massachusetts.

Project WELCOME is a collaboration between Wheelock College, a private college specializing in early childhood education and the Children's Hospital Medical Center, one of the largest research and teaching hospitals in the country. It is a model program for high-risk premature infants emphasizing a developmental/educational approach and designed to integrate that approach into the specific health care and human service systems with which it interacts. The characteristics of each of those systems are outlined below, followed by discussion of program philosophy, a description of the developmental consultation model, a discussion of how Project WELCOME has individualized this model, and future directions for the project.

CHARACTERISTICS OF SYSTEMS SERVING PREMATURE INFANTS

In Massachusetts, the primary systems which serve high-risk premature infants and their families are the newborn intensive care units in tertiary medical centers, referring hospitals in the community, visiting nurse associations, and early intervention programs.

The Children's Hospital NICU. The Newborn Intensive Care Unit (NICU) at Children's Hospital is a 16-bed unit designed to provide care for infants during the most critical phase of their hospitalization. All infants seen in the NICU have been transported to Children's Hospital from one of a large number of referring hospitals located in eastern Massachusetts or in neighboring states. After the infants are medically stable, they are sent back to the referring hospitals for the recovery phase of their care and, when ready, are discharged home from the community hospital nursery.

The NICU has a well-developed program of primary care including a strong program of primary nursing. Each family is assigned a primary physician and primary nurse who plan, coordinate or carry out and monitor the infant's care and who meet regularly with the family. Social service support, parent groups during and after hospitalization, and a parent-to-parent telephone support program are also available to families within this system. The primary nurse assumes a major role in family support, developmental programming and discharge planning as well as in planning and providing for the physical care of the infant. These nurses are highly skilled, motivated and resourceful. They have access to a wide range of resources within Children's Hospital and in the Boston area and view developmental intervention as part of their responsibility in providing for the infants' needs.

Referring Hospitals. The referring hospitals vary widely, ranging from a large, intermediate unit with primary nursing to many smaller community hospitals with a variety of philosophies of nursing practice. In general, these hospitals tend to have relatively low staff turnover, access to fewer resources than the in-town medical centers and less emphasis on developmental aspects of infant care. The nursing staffs of the community hospitals are well prepared for the care of normal newborns and want to build their skills in all aspects of the care of the post-NICU infant.

Visiting Nurse Associations. The major resources for high-risk infants after discharge from the referring hospitals are the visiting nurse associations and early intervention programs. Referrals to visiting nurses are made to provide families with assistance in the physical care of their infant and in the monitoring of the child's development. However, while visiting nurses are routinely requested to see high-risk infants, the majority of their caseload is the care of the elderly. Thus, their experience and training tends to be in adult care, rather than in pediatrics.

Intervention Programs. Over 50 early intervention programs sponsored by the Department of Mental Health and Public Health are available statewide for infants at established risk. Infants at environmental and/or biological risk are eligible for services in many of these programs. The composition of program staff varies and includes persons with backgrounds in early childhood education, special education, nursing, social work, physical, occupational, and speech and language therapy. Links between the intervention programs and hospitals, health care centers, and private practice are variable, depending upon the preference of individuals, rather than on an organized system of referral criteria and procedure. The average age of referral to early intervention programs in the greater Boston area in 1980 was 18-22 months.

Project WELCOME. The purpose of Project WELCOME is not to add another layer of service, but rather to support existing providers by filling gaps and coordinating services, thus building a continuous system of support. The project's goals are to: 1) increase family support, 2) strengthen the focus on developmental

aspects of infant care, and 3) increase linkages and information sharing among the providers. Family support activities include additional social service time on the NICU, educational and support groups for parents after discharge, a parent newsletter, and a parent-to-parent telephone support program. Activities aimed at increasing linkages and information sharing have included development and dissemination of a statewide directory of early intervention programs; a 10-week continuing education course for nurses, titled The Preterm Infant: Development, Assessment and Intervention; bi-monthly seminars for early intervention providers on medical, developmental and psychosocial issues of the NICU infant; an NICU/Early Intervention Liaison Program of NICU tours and early intervention visits; the development of joint referral criteria and referral procedures by an Early Intervention Council of providers from the tertiary center, referring hospitals, and community nursing and early intervention programs; and a statewide survey of early intervention services to premature infants. Future plans include short-term group and ongoing individual education of visiting nurses in preterm infant development, a social work liaison program and an outreach program for community pediatricians regarding referrals to early intervention programs.

PHILOSOPHY OF THE DEVELOPMENTAL CONSULTATION MODEL

The central figure in the Project WELCOME model is the Parent/Infant Educator. The educator's role as originally conceived focused on a direct service, hands-on approach in the nurseries. Through experience, feedback and re-evaluation, the model has been revised. The Parent/Infant Educator is now seen primarily as a consultant, offering support and assistance to existing service providers. Further adaptations of the model will undoubtedly be made as new referring hospitals are added. The underlying principles of the model at this point in the project's development are discussed below.

The Developmental Perspective. The project seeks to strengthen the developmental perspective of individuals and systems involved in the early care of high-risk premature infants. We define the developmental perspective as a way of thinking about and acting toward infants and their families which recognizes the infant's full humanness, competencies and coping strategies and right to optimal development. A developmental perspective is a viewpoint, as well as a body of knowledge and practice, which people in a range of disciplines can and do possess. In our experience, it is inaccurate to assume that this perspective is one that only the developmentalist--educator, psychologist, or other--has or can bring to a nursery. A more appropriate model begins by recognizing the existing competencies of individual care providers or programs and then builds collaborations based on their desires and needs.

Individualized Approaches. How the goal of supporting existing providers in strengthening their developmental perspective is accomplished varies according to what people want for themselves, their learning style, needs and other available

resources. Because our work is individualized, different settings use the Parent/Infant Educator's resources in different ways and to different degrees. For example, at Children's Hospital, the level of sophistication of the NICU in incorporating developmental considerations in its care is high. Over the past year, a group has formed who provide nurse-to-nurse consulting on developmental issues on a peer level. In this setting the Parent/Infant Educator has acted as a resource person to the developmental group and as a developmental consultant, when needed. In contrast, the need for developmental consultation is much greater in the referring hospitals. Here, infants go through the "growing and gaining" period so crucial for the baby and for the parents. Appropriate developmental intervention and parent support are essential for the continuity of care and the enhancement of parent/infant interactions. It is in these settings that the Parent/Infant Educator for Project WELCOME has spent the majority of her time.

Background and Training of the Parent/Infant Educator. To work effectively and flexibly as a developmental consultant, one must have considerable experience in the field of Child Development. The Parent/Infant Educator at Project WELCOME has an extensive background. Besides a B.S. in Education and an M.S. in Child Development, she had seven years previous work experience in early intervention which included infant assessments, curriculum planning, home- and center-based teaching, parent support and program coordination. In addition, she had achieved reliability on the Neonatal Behavioral Assessment Scale (NBAS) (Brazelton, 1973) and had used the scale in community hospital nurseries to demonstrate to new parents the behavioral competencies of infants with Down's Syndrome. Prior to assuming a consultation role, the Parent/Infant Educator completed a three-month orientation program designed by the Director, Nurse Consultant and Parent/Infant Educator in collaboration with the Clinical Coordinator of the NICU. This included observation in the NICU, individual contact with nurses, and extensive reading on the medical treatment, nursing care and developmental outcome of premature infants. The Nurse Consultant provided one-to-one teaching about the equipment, policies and practices and ecology of the unit. The philosophy of primary nursing was reviewed; opportunities to observe medical and multidisciplinary rounds were provided. Visits to hospital-based Handicapped Children's Early Education Program (HCEEP) projects in Charlottesville, VA (Education for Multihandicapped Infants) and Washington, DC (Training and Infant Intervention Program) were arranged. In addition, the Parent/Infant Educator was trained to be reliable on the Assessment of Premature Infant Behavior (APIB) scale (Als & Brazelton, 1981; Als, Lester, & Brazelton, 1979; Fitzgerald, Lester, & Yogman, 1981).

Conceptual Framework. Developmentally appropriate interventions must be guided by a conceptual framework of premature infant behavior. Project WELCOME employs an individualized assessment and intervention model based on the structure of the NBAS and the synactive theory of development, as described in Part I of this book. In this theory, the behavioral organization of the premature infant is described as an interplay of various subsystems functioning within the

infant, including the motor system, state organization, coping and regulatory ability. The goals of the Parent/Infant Educator's consultation are to help caregivers observe these different levels of functioning and provide supportive measures to enhance the infant's competence and adaptations and to prevent developmental dysfunction. Interventions in this model are based on the individual infant's strengths and weaknesses. This avoids the possible ill effects of a routinized or "one size fits all" stimulation program--an approach which has the potential for overloading the infant's still fragile central and autonomic nervous systems (Als, Lester, & Brazelton, 1979). Developmental intervention--as differentiated from infant stimulation--includes observation, translation and interpretation of behavior as well as physical and environmental manipulation. Strategies which control or limit stimulation are as essential in this approach as those which increase it.

Training the Trainers. Developmental assessment and intervention should be an integral part of the routine care for hospitalized preterm infants. Nurses will be most affected by incorporating a developmental perspective into the NICU, since they are the ones who provide this care and who--along with the parents--know the infants best. Clearly, nurses must be involved at each point and must be in charge of the process of incorporating developmental information into their work. The model we have adopted for the referring hospitals is a "training the trainers" model, where the Parent/Infant Educator works intensively with nurses who have been identified to become resource persons in their own settings. In this way, the model is incorporated into the ongoing management of the nursery.

DESCRIPTION OF THE DEVELOPMENTAL CONSULTATION MODEL

In the Project WELCOME model of developmental consultation, the Parent/Infant Educator plays a predominately facilitative role in the nurseries. Actual interventions are carried out by the nurses. Through demonstrations, one-to-one teaching, direct assessment and joint assessments, the Parent/Infant Educator teaches the conceptual frameworks of the NBAS and APIB and assists nurses as they practice for proficiency in the scales. The Parent/Infant Educator acts as a preceptor to the nurses. They receive their formal reliability training through Dr. Brazelton's staff or from Dr. Als at the Children's Medical Center, Child Development Unit.

There is no magic in this approach. Many experienced nurses have long known what current research is revealing--that preterm infants communicate far more about their needs through their behavioral responses than has been realized. Many NICU nurses have observed these behavioral signs and designed their care accordingly for years. In addition to validating what they already know, the frameworks of the NBAS and APIB allow nurses to become more systematic and comprehensive in incorporating developmental considerations into their care. As a result, the nurses increase their skills in making accurate developmental observations during routine care, articulating the infant's behavioral repertoire, documenting the developing patterns of behavioral organization, and planning

appropriate behavioral and developmental interventions. Nurses are encouraged to share developmental information with parents, thus promoting the parents' optimal involvement with their baby during the growing and gaining period. The process we are using to implement this model from the point of referral in the NICU through return to the referring hospital and eventually to discharge to the home is described below.

Referral in NICU. In the NICU, the Project WELCOME Social Worker acts as case finder. She and the primary nurses determine which infants meet the eligibility criteria established by the project. (The criteria include birthweight under 1250 grams, intraventricular hemorrhage, seizures in the newborn period, sepsis, or apgar scores below 3 at 5 minutes. Infants hospitalized in the NICU for a week who are at environmental risk--due to parental age, evidence of substance abuse, severe financial need, or disability in parents interfering with caregiving--are also eligible.) The Social Worker and/or primary nurse meets with the parents, explains the services of the project and, if appropriate, offers an introductory parent letter describing the project. If the parents agree to participate (thus far none have refused), the Social Worker informs the Parent/Infant Educator of the new referral and shares all pertinent information on the infant: present medical status, birthweight, gestational age, referring hospital, relevant psychosocial information, name of the primary and associate nurses who have been assigned to care for this child and whatever developmental information is available at this early stage. The Parent/Infant Educator is available as a consultant on an "as needed" basis to the primary nurse during the infant's stay in the NICU.

When an infant becomes medically stable and nears discharge to the referring hospital nurseries, the Parent/Infant Educator schedules a meeting with the primary nurse to review the infant's medical status and the nurse's assessment of the infant's "behavioral signature" (Brazelton, 1981), that is, the infant's coping ability and behavioral responses to nursing and medical interventions. In addition, developmental interventions implemented in the NICU are discussed. The Parent/Infant Educator's assessment at this point may be by observation or by an actual hands-on assessment, depending on the baby's medical status. Hands-on assessments are not recommended unless the baby is on room air and in an open crib. An observational assessment using the framework of the APIB can be made in which the infant's behavioral responses are noted, with special attention paid to the regulatory or coping strategies demonstrated by the infant in an attempt to maintain organization in the face of stressful and often invasive procedures. These strategies may include postural change, grasping of finger or oxygen tube, visual locking, motor discharge, state change or range finding. (An example of range finding is when the infant searches for and finds a boundary such as an incubator wall against which to brace the hands and/or feet in order to stabilize him/herself and maintain organization [Newman, 1981]). Observations of robustness are also made. Does the infant have the energy to respond to the intervention? What is the quality and robustness of that energy? This information can be written into the developmental notes that the NICU nurse includes as part of the discharge planning package.

Stay in Referring Hospital. When the infant is past the critical phase and is transferred to the referring hospital for the recovery phase of care, the Parent/Infant Educator is notified by the Project WELCOME Social Worker and/or hospital staff. Weekly observational or hands-on assessments are administered by the Parent/Infant Educator and the nurse in the referring hospital. These joint assessments are used as one-to-one teaching sessions to discuss the infant's physiologic lability--how it is manifested and under what conditions--the tone and motor maturity, degree of observed activity, alertness and availability for interaction and specific self-regulatory behaviors such as quieting abilities, robustness, control over input and how much help the infant needs in order to prevent disorganization. The assessment findings are discussed with the nurse and appropriate interventions planned. These interventions are translated into the nursing care plans by the nurse and are then implemented. In addition, the Parent/Infant Educator writes a summary of the assessment in the Progress Notes which become a part of the baby's permanent medical record. Nursing care plans are updated weekly from ongoing assessments.

Interventions Used. Some examples of interventions used in this model of observation of behavior are: When presenting motor disorganization (flailing), the infant can be repositioned in side-lying with a rolled blanket at the back and feet to help maintain position and flexion. Maximum interventions for some infants are repositioning in the prone position, providing total frontal inhibition and tactile boundaries for stabilization such as a rolled blanket at the head, sides and feet. An infant who has scooted to the bottom or corner of the incubator is demonstrating the need for such boundaries. Some infants who are very poorly organized need total containment, and for them, swaddling provides this needed security. When observing physiologic disorganization, e.g., changes in color, respirations and cardiac rate, removing the source of stimulation, repositioning the infant, and allowing a quiet time (time out) to recover is recommended. If the infant averts the gaze in response to social interaction, it is helpful to present a quiet, less animated face and not to use one's voice; this assists the infant in recovering balance. Gaze averting may be the signal that the child is not yet ready for animate visual stimulation. Infants who can't deal with the overloading stimulation of an animated face can look at stabiles or decals placed in an optimal position on the incubator or crib. Attending to this type of visual stimulus is often the precursor for attending to the quiet, softly animated face of a caregiver. Preterm infants can sometimes only tolerate one or two sensory inputs from the environment; auditory stimuli added to visual stimuli can be overloading, causing the baby to become behaviorally disorganized and stressed.

Observing and documenting the degree and areas of organization and disorganization in the individual infant predicates the interventions that are needed. These observations provide a "window" (to quote Brazelton again) into the infant's developing competencies in dealing with the environment. Interventions such as those described above are taught to parents by the nursing staff, reinforcing optimal appropriate interaction between the parents and the infant.

Parent Involvement and Education. In addition to supporting the nurses in communicating developmental information to parents, the Parent/Infant Educator is also available to meet with families to discuss their infant's behavior and development. If appropriate, the parents observe an assessment by the Parent/Infant Educator who demonstrates the infant's competencies and behavioral responses. This assists the parents in understanding how the infant is using coping strategies in order to maintain organizational balance and how best to interact with their child. Parents see how their baby's behavior is manifested in response to being physically manipulated and discuss their own observations and ideas about ways to care for and interact with their baby.

Once the parents have observed an assessment, a Parent Plan (Figure 1) is prepared by the Educator in conjunction with the nurse and the parents and is updated weekly, when possible. Parents are encouraged to implement the plans during their visits and to use them as guides once their baby is discharged. The plans become an ongoing record for parents of the infant's developmental and behavioral organization while in the referring hospital.

Discharge Planning. The discharge planning process begins when the infant is first admitted to the NICU and continues during the infant's stay in the referring hospital. Most infants are referred to a Visiting Nurse and to the Infant Follow-Up Program for follow-up care. Referrals to community early intervention programs are considered; however, the need for such a service is not always apparent at discharge time. For families who are not referred to early intervention, the Parent/Infant Educator plans two follow-up home visits after discharge. The arrangements for these visits are made with the parent while the infant is still in the referring hospital. Prior to discharge, a final developmental assessment is administered, and a summary with recommendations is written in the progress notes in the chart. A final parent plan is also written and shared with the parents.

Home Visiting After Discharge. When the infant has been home for approximately two weeks, or has reached full-term status, a home visit is made by the Parent/Infant Educator. Scheduling of the visit is flexible, depending on the parents' need to spend some time alone with their child without any outside intervention.


On the first visit, the NBAS is administered, and the infant's competencies are assessed and demonstrated to the parents. A second home visit is arranged for the following month. These home visits provide an opportunity for the Parent/Infant Educator to monitor the development of the infant and to assess what additional support services the family might need. If a need is indicated, then a referral to community resources is encouraged, such as a referral to an early intervention program if there appear to be developmental problems. Home visits provide the opportunity for the Parent/Infant Educator to assess the parents' understanding of the infant's behavior, how well they are reading behavioral cues and what appropriate interventions they are making. After the second home visit, the Parent/Infant Educator terminates direct contact with the

Figure 1
A Parent Plan

A

Developmental Plan

for: Joey



My Competencies are:

- I get my hand to my mouth
- I can look at quiet faces briefly
- I quiet when wrapped and held gently
- I suck and swallow well

These things stress me:

- Being on my back
- Being undressed
- Moving me too quickly
- Loud voices

What I like to do:

- Be on my tummy
- Be wrapped up in my blanket
- Have my pacifier
- Be held gently and quietly


Signs of stress:

- Finger splaying
- Flushing or paling
- Gaze averting (looking away)
- Tip of nose whitens

(To all of the above, allow time out for Joey to recover; a quiet, non-stressful time)

How you can help me:

- Place me on my tummy or side
- If on side, put rolled blanket at my back and feet
- Use your soft voice when talking to me
- Move your face from side to side to encourage me to follow it
- Hold me firmly, but gently, don't move me too quickly
- When changing my diaper, use your hand to swaddle me



family. Indirect contact is maintained through the Parent/Infant Educator's attendance at the Infant Follow-Up Program when the infant returns for developmental monitoring. (To date, the results of contact with parents in referring hospital nurseries--as revealed in the home visits--has been encouraging. We are seeing infants who demonstrate less stressed behaviors at home and parents who appear to be very knowledgeable about their infant's behavior and respond most appropriately.)

For families referred to early intervention at the time of discharge from the hospital, the Parent/Infant Educator makes an initial home visit with a member of the program and phases out direct involvement with the family after this visit. Should there be a waiting list for early intervention services, the Parent/Infant Educator can provide home visiting until there is an opening in the program. With parent permission, the Parent/Infant Educator shares developmental information with the early intervention team and arranges their attendance at the Infant Follow-Up Program. The Parent/Infant Educator maintains monthly phone contact with the intervention program for a six-month period, after which Project WELCOME's involvement with the family is terminated.

INDIVIDUALIZATION OF DEVELOPMENTAL CONSULTATION MODEL

The Project WELCOME model has been tailored to meet the individual needs of three referring hospitals. Although specific roles and arrangements vary, the goals and philosophy of the model remain the same. A consistent approach across settings is that of peer teaching or "training the trainers." Working closely with the nursing leadership, key individuals have been identified in each referring hospital to receive formal training in the APIB and/or the NBAS. These nurses, in turn, will provide teaching and support for their peers and become the ongoing developmental consultants and resource persons. Our goal is to provide resources to the persons who are the long-term providers. This section describes the various roles and relationships between the Project and each of the three hospitals served.

Referring Hospital #1. Referring hospital #1 is a community hospital with a 20-bed normal newborn nursery. A separate space holding up to 6 beds is provided for preterm and for other infants requiring special nursing interventions. To initiate the project's involvement with the nursery, the Nurse Consultant conducted a nursing needs assessment to determine the interests and needs of the staff. Based on this assessment, a five-week in-service series was designed and implemented. The sessions included:

1. An explanation of the project and the roles of staff members and a film on infant assessment.
2. Demonstration of the NBAS with a full-term infant and parents.
3. Summary and interpretations of the NBAS demonstration and discussion of the incorporation of the information into a nursing care plan.
4. Presentation of a developmental plan for a preterm infant.

5. Discussion of referrals to early intervention with a panel of early intervention program directors serving the catchment area of the hospital.

The project's Director, Nurse Consultant, Parent/Infant Educator, Social Worker and Early Intervention Liaison participated in the introductory meetings. The In-Service Coordinator for Nursing at the hospital was an essential person in coordinating the nursing education program and in obtaining approval through the Charting Committee for the Parent/Infant Educator to write in the records.

As an outcome of the in-service, the Assistant Head Nurse was identified as the primary contact. She now works closely with the Parent/Infant Educator on an ongoing, one-to-one basis to assess infants, discuss findings and develop intervention plans. The Parent/Infant Educator visits the hospital shortly after the return transport for each project infant.

In addition to the one-to-one teaching, two other types of activities have been important in the outreach to this hospital: a joint panel presentation on "The Competent Premie: Translating Theory into Practice", with the Assistant Head Nurse, Director, Parent/Infant Educator, and Dr. Heidelise Als, the senior author of the APIB, at a regional symposium and participation of the Assistant Head Nurse and two other nurses in the 10-week continuing education course. To prepare for the symposium, the Parent/Infant Educator and Assistant Head Nurse photographed an assessment, documented before and after nursing care plans, and made a joint home visit. The pictures and script will be used in subsequent presentations to staff nurses and to pediatricians. At present, the Assistant Head Nurse and the new In-service Coordinator are working toward their reliability in the NBAS. After this is achieved, our goal is to support the Assistant Head Nurse in designing and initiating a teaching and support program for the staff nurses.

Referring Hospital #2. This is a 12-bed intermediate unit, with primary nursing services. This hospital transports only a few of its infants to the NICU at Children's Hospital, those who are the most critically ill. Many of the other infants stay from 6-8 weeks in this nursery. To be maximally useful, it was important to offer support and consultation to the staff regarding other preterm infants in their care in addition to those who had returned from the NICU. In this hospital, the introductory model differed in that one planning meeting was held with the Head Nurse, and only one introductory in-service was provided by the Nurse Consultant, Social Worker and Parent/Infant Educator. The nurses preferred to work on a one-to-one basis on individual cases. No single contact person was identified at this early stage; the Parent/Infant Educator was expected to work with the primary nurse assigned to each project infant. Therefore, the Parent/Infant Educator worked individually with most of the nurses on the staff. Because this hospital is close by and because of the number of babies in the unit, the Parent/Infant Educator set up a regular schedule to visit the nursery two days each week, rather than on an as-needed basis. In addition to the case-by-case

consultation, four staff nurses participated in the continuing education course and presented readings and information from the course at staff development meetings with their peers. The Head Nurse collaborated with the Parent/Infant Educator on a presentation at a statewide conference which included a slide presentation of an assessment and interventions in the nursery. This presentation has since been given to the Obstetrics/Gynecology staff and will be used in workshops at a national conference on environmental interventions.

At this point, the Head Nurse has identified herself as the individual to be trained in the NBAS and the APIB. Serving as both Head Nurse and In-service Coordinator for the unit, she is committed to incorporating a strong developmental component into her orientation of new nurses and into the ongoing in-service for present staff.

Referring Hospital #3. Like Referring Hospital #1, this is a community hospital with a newborn nursery. The setting at Hospital #3 is unique in that an early intervention program is located here. After a formal introductory meeting with the Chief of Pediatrics, Obstetrics, Nursing and Planning, planning sessions have been conducted with the Vice-President of Nursing, the Nursing In-service Coordinator, Head Nurse of the Newborn Nursery and the Director of the Early Intervention team. Thus far, the plan is to conduct a revised version of the 10-week course on the premature infant for nurses in the newborn nursery, social workers serving the nursery and pediatric floors, and members of the early intervention team. The course carries 25 contact hours from the Massachusetts Nurse Association and, if desired, two undergraduate or graduate credits from Wheelock College. Nurses from the NICU and Referring Hospitals #1 and #2, as well as Project WELCOME staff, will serve as presenters. At the end of the course, participants will hold a planning retreat to determine their goals and to define the project's involvement in helping them achieve these goals over the next 6-8 months. We anticipate that the hospital and the early intervention team will define new ways to work together to support families, monitor children's development, and assure that appropriate follow-up services are provided. Project WELCOME will serve as a catalyst and resource for this new collaboration among neighboring services. Through these and other services discussed, the project hopes to achieve its goal of strengthening the focus on developmental aspects of infant care throughout the Boston area and to provide a model for similar programs in other parts of the country.

FUTURE DIRECTIONS

Based on our experience in the NICU and in the community, we have identified directions for future activity which cluster in two areas: 1) completing the incorporation of the developmental consultation program into the ongoing management of each nursery, and 2) addressing the complex and challenging issues related to early intervention referrals for premature infants.

Integration into Ongoing Management of Nursery

Under the first category, three areas of activity will be addressed: promoting nurse-to-nurse communication about development, adapting use of the parent plan, and ongoing support for the developmental aspects of care.

Nurse-to-Nurse Communication. Nurse-to-nurse communication is a basic component of the discharge process. At present, the Parent/Infant Educator plays an intermediary role between the NICU and community hospital nurses at the time of transfer. She meets with the NICU primary nurse to learn about the baby's development in order to provide more effective consultation to the community nursery. The focus will shift to supporting the community nurses in acquiring this information themselves. The Project WELCOME staff will offer to assist each community nursery in designing its own format or protocol for the exchange of developmental information with the NICU and with visiting nurse associations, early intervention teams, and community pediatricians. With training and support, community hospital nurses can play a pivotal role in collecting and sharing developmental information with parents and professionals.

Adaptation of the Parent Plan. Project WELCOME has encouraged the use of a written Parent Plan to enhance the communication of information about the baby's developmental strengths and needs (Figure 1). Nurses have so far been enthusiastic about the plans and supportive of their use. We plan to review this written format with each nursery and re-evaluate its use on a long-term basis, asking: Can the nurses incorporate this system independently into their routine care? Should the form be revised? How do they want to proceed after our resources have been terminated?

Our goal is to help each nursery develop and implement its own approach to sharing developmental information in a consistent way with parents before the project's involvement is over. A planned transition should help insure that the emphasis on development stimulated by the project is translated into workable plans that can be implemented in the course of routine care.

Ongoing Support for a Developmental Perspective. Change in any setting requires some degree of support. Change toward developmentally oriented care in a medical setting clearly requires ongoing support. Project WELCOME has served as a source of new information, new skills and new relationships in the nurseries in which we have worked. It is imperative that supportive networks be established within and across nurseries to maintain this level of encouragement, feedback and input about development. We plan to arrange exchange visits among nurseries and conduct joint sessions for the staff from the three community hospitals. The three Head Nurses will be encouraged to identify a common activity which they can maintain over time to support their own and their staff's growth in developmental aspects of care. Options might include: joint attendance at infant sessions in the Boston area, joint assessments on the NBAS or APiB to maintain reliability, rotating sessions for staff on infant/parent issues, or consultation to one another's nursery. The project will serve as a catalyst to insure that these liaisons are in place before our involvement ends.

Early Intervention Referral of Premature Infants

The project will involve itself with three main concerns regarding early intervention referrals for premature infants: timing of the referrals, early intervention program modifications for premature infants and community linkages.

Timing of Referrals. One of our goals at the initiation of Project WELCOME was to promote early referral of at-risk infants identified in the NICU. As our understanding of the issues has grown, we have acquired a new recognition of the flexibility needed to make this system work. While present focus continues to be on the earliest possible appropriate referral, we are directing our energies toward generating a range of referral options which can be considered in relation to the individual needs of each family. Clearly an organized system of "safety nets" needs to function at the community level as well as at the NICU. For example, an early referral for a high-risk infant within a high-risk family should originate from the hospital and should involve the early intervention team in the discharge planning process. An early referral for a high-risk infant within a low-risk family might be initiated at the point of discharge or might be deferred until the family has time to settle in at home. Depending upon the situation, the family may be given information about the program and encouraged to make contact with the program after they have gone home, or, with parent's permission, the program may be contacted by the hospital at discharge and asked to delay their initiation of services with the family for a period of time. Other variations might include a "pediatrician's alert" referral in which the NICU physician or nurse alerts the community pediatrician to the possible need for early intervention and requests that he/she closely monitor the child's development. In addition, the NICU can inform the pediatrician of the program serving the family (using the Project WELCOME statewide directory!) to further encourage his/her consideration of such a placement. This same "alert referral" can be used with other community providers, such as visiting nurses or social workers. A low-risk family and low-risk child may be monitored routinely by the Infant Follow-Up Program. Thus, referrals may be made at later points if the need arises. Lastly, a low-risk infant in a high-risk family may be followed in several ways: hospital referral to early intervention, community alert referral, or referral to social service agencies or family support services with the Infant Follow-Up Program monitoring the child's development.

Other options are certainly possible and need to be clarified. We do not believe that all NICU graduates--or all premature infants--need early intervention. However, we do believe that early intervention should be considered as a referral option for each family and baby at the point of discharge.

Program Modifications for Premature Infants. Program modifications for premature infants may be required to encourage earlier and more appropriate referrals to early intervention. In our experience we have found a hesitancy on the part of some parents, particularly parents whose child does not have an

established risk diagnosis, to accept early intervention services. Some parents fear that their child's development will be restricted in a program serving "handicapped" children; others feel that professionals have had enough impact on their lives and that they want to care for this baby themselves; and others simply do not view their child as having special needs. Professionals, particularly in hospitals, may share the same reservations. Recognizing these concerns, how can programs adapt themselves to offer support to families of premature infants?

Programs in Massachusetts are creatively responding in several ways. Some are designing separate intake systems which are more flexible, allowing longer times for program entrance and more options regarding the amount of service desired. A program may not require a full team evaluation of a young premature infant prior to the initiation of service, or may not require attendance at center-based programs. Programs may offer connections with other parents of premature infants who have had early intervention. Special mother/baby groups and preemie parent support groups are being established in selected community programs. A lower intensity model featuring monthly rather than weekly home visits, integration into playgroups with normally developing children, and specialized day care services have all been supportive alternatives for families. Some programs have begun satellite services with a separate name to differentiate services for preemies from services for other children with special needs, particularly if the original program is affiliated with an Association for Retarded Citizens or United Cerebral Palsy organization. Special links with NICUs and community hospitals are being established, capitalizing on nurse-to-nurse communication.

Providers are realizing that an early intervention referral may bring up feelings of failure in parents and professionals and that this accounts for part of the hesitancy. Both parents and professionals are asking for support without stigma. Certainly this is an appropriate challenge for early intervention services. The increased flexibility and individualization of services which the families of premature infants are demanding may be needed by other families as well. Such changes represent a strengthening, not a weakening, of the early intervention network.

Community Linkages. While Early Intervention (EI) teams eagerly seek earlier and earlier referrals, the development of a predictable system of safety nets in the home and in the center is not an easy task. Project WELCOME's goal is to organize planning sessions with each referring hospital and the EI teams that serve it, to design a workable system for referral and follow up. We have determined that the various service delivery settings need to be part of a closer and more coordinated system or services. Serving as a catalyst, Project WELCOME will encourage networking and will assist existing agencies to translate their good intentions into action plans.

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Family Support



RANGE OF FAMILY SUPPORTS: THE EFFECTS OF HOSPITALIZATION ON SIBLINGS

Mary C. Cerreto & Vicki A. Switzer

The current emphasis on providing support for the families of hospitalized children typically neglects the child's brothers and sisters. This neglect is visible in hospital regulations which prohibit child visitation and in the lack of attention to siblings when conveying information about a hospitalized child's condition. Yet it is obvious that siblings are affected by the experience. Hospitalization of a brother or sister may bring sudden fears and anxiety, an immediate disruption in family security and routine and unplanned separation from parents. When the affected child has a developmental disability, mental retardation or chronic illness, hospitalization may be frequent, thus multiplying family separations and stresses.

Recent research indicates that the brothers and sisters of children with chronic conditions are at high risk for emotional and behavioral problems (Cerreto & Miller, 1982). The health care/education relationship can enhance awareness of the concerns of brothers and sisters of hospitalized children and can develop strategies to prevent and improve attendant problems. This chapter will discuss the following elements vital to an effective family support system: the impact of hospitalization on siblings from the conceptual basis of loss and separation; differential effects due to the developmental stage of the siblings; awareness of feelings of children who have siblings with a chronic mental or physical handicap; and intervention methods to help children deal constructively with those feelings.

The chapter presents information on current developmental theory and research as well as knowledge gleaned from our own experience in working with siblings of handicapped children, and it suggests ways that professionals and parents can use this information to help siblings of different ages cope with their feelings and experiences.

LOSS AND SEPARATION AND THE DEVELOPMENTAL STAGES

The concept of separation and loss is an excellent starting point for a discussion of the effects of hospitalization on siblings. The separation and loss experienced may take many forms, including loss of the physical presence of one or both parents, loss of sibling companionship, loss of some time and attention

from all family members and loss of the comforting sense of security and daily routine.

Children handle these losses differently depending on their stage of development and the cognitive and emotional resources available at each stage. How a particular child will be affected is related to: the basic tasks of development and needs at each stage; the particular age and stage-related meaning of loss and separation to the child; and the specific behaviors of the adults in the child's environment. These three points are discussed below as they relate to each developmental stage, from infancy to adolescence.

The Infant. Infants spend their first year and a half in a dependency relationship with adults. During this time, they face some of life's greatest challenges in terms of personal-social development: establishing trust in others to fill their basic needs, developing emotional ties to others, experiencing and mastering the first stage of stranger anxiety, and developing the beginnings of a sense of intentionality of their own acts. Infants' needs during the early part of this period include nurturing, touch and sensory stimulation; during the latter part, the freedom to move and explore becomes important.

Infants are often overwhelmed because developing resources do not yet permit organization of emotions and experiences. They have no sense of time differentiation. Five minutes is five hours is five days is forever. For them, loss and separation mean abandonment. Symptoms of loss may include withdrawal, lethargy, crying, feeding problems (eating more or less), restlessness or irritability. Even children who have never bonded and never established a close relationship often will respond to the best of parental substitute care by intentionally closing out or refusing eye contact. In extreme cases, the infant experiences clinical depression. Children labeled "nonorganic failure-to-thrive" often show these characteristics, and our clinical experience confirms the difficulty in reestablishing a trusting relationship between such infants and their caregivers.

Most helpful for the infant sibling is consistency of care. Parents who must be separated from their other children during a child's hospitalization are encouraged to leave the sibling with one alternative caretaker for the duration and not to switch the child from grandparents to aunts to babysitters, etc. It is important to see the same people day after day and establish a consistent routine. Parents are not usually encouraged to bring young siblings to the hospital. Health risks may exist, and the older infants' need to move and explore is interrupted by hospital regulations.

The Toddler. Toddlers (two and three years of age) are in the midst of the egocentric "my" stage, a time of being pleased with themselves and all the new things to imagine and do! They work hard to overcome a constantly ambivalent situation: they want independence but are dependent on adults. They want both

approval and autonomy--often incompatible because much of the exercise of new skills provokes anger from caretakers. During this stage of great exploration, toddlers assert themselves. Sometimes they overassert, become terrified, and need comfort and security. Toddlers absorb the emotions around them, relate poorly to peers, and have difficulty sharing. They face tasks in developing autonomy and testing limits. Adults can help by providing firm and consistent limits and by accepting the toddler's ambivalence.

Toddlers, too, are affected by not having a concept of time, and they face loss and separation with fears of abandonment and isolation. When a parent is absent to be with another child in the hospital, the toddler left at home often experiences the situation in terms of his or her own unmet needs. A new baby is often seen as the agent in the loss of parental presence, time and affection. Toddler responses early during separation may involve sleeplessness and lethargy and, later, anger and aggression.

Allowing children of this age to act out and verbalize concerns and feelings helps them cope with those feelings as elements of reality and not fantasy. Toddlers have little control of the emotions they pick up so readily from environmental cues. Therefore they need and will use adult models. Adults should help the child by giving words or actions to imitate, by feeling with the child and by enabling the expression of these feelings in shared talk or tears without losing control of their own emotions (which will often frighten the child).

High levels of separation anxiety can be decreased by preparing the child for even the smallest separation with facts repeated over and over again. Any sense of panic experienced by toddlers can be lessened by helping them to reestablish a sense of control. This can be done by offering them simple environmental choices--between juice or milk, the green shirt or the blue shirt, for example.

The Preschooler. During the preschool years, children continue to develop skills of independence and exploration. The sense that "I can do it" is revealed in the games of King of the Mountain, Superman and Wonderwoman. Preschoolers are rebellious and accident-prone. Although social control is external, they are also developing more self-control.

At this age, children are becoming more affectionate and can imitate but not empathize. They still have great difficulty with the concept that others have feelings different from their own at the moment. Also typical of emotional development at this age are frequent nightmares and phobias and the fear of body-part loss.

Preschoolers' tasks include resolving magical thinking and becoming reality-oriented, seeing where they exist in that reality, developing more impulse control, developing a sexual identity, and beginning the move away from family to peers. Adults in the child's environment fill stage-related needs by setting and maintaining clear limits, providing protections (in light of the high accident rate due to irresponsibility and lack of judgment) and fostering a developing sense of competence, control and power.

The preschooler is concerned with the unknown and faces loss and separation with feelings of uncertainty--more questions, more whys and, "Will it happen to me too?" Separation from the major caretaker, sex-role model or friends are important losses to the child at this time. The preschooler often feels responsible for family members. The hospitalization of a child may be seen as punishment, and the sibling may feel guilt over having caused or wished the illness. When the preschoolers' attributions and emotions become overwhelming, they may displace them and respond instead with an attitude of "who cares?" The preschooler often reacts to loss and separation with lethargy, aggression, guilt, fantasy, withdrawal and an increase in toileting accidents. The child may also become more loving and affectionate.

When a preschooler faces the hospitalization of a sibling, adults should help the child who stays at home to verbalize feelings and to reiterate constantly the concept of his or her own safety. Because it is so common for the preschooler to feel responsibility for the illness and hospitalization, adults need to help children act out (role playing, dolls, puppets) their impressions of the situation, to provide them with reality-based explanations, and to ignore the "who cares?" attitude.

The Five Year Old. By five years of age, children are moving into a stage governed by a developing conscience and the importance placed on discovering rules, order and relationships. A growing ability to compare (and the child does compare parents, houses, teachers, etc.) may result in a constant barrage of "It's not fair." And when a sibling is hospitalized, and parental time and affection are focused necessarily on the sick child, the world indeed looks like an unfair place. The five-year-old often does better in external situations like school and then, given that the child's controls only go so far, explodes at home. The child needs adult help to deal realistically with the inequalities of situations, to play games and learn rules, and to allow but not reinforce sporadic explosiveness.

At this age, children see loss and separation as unfair and the absent parent as uncaring or angry. They often continue to see things as their own fault and to feel guilty. A common response may be the loss of inner control and a heightened degree of explosiveness or, in an attempt to maintain control, an overcontrolling or externally rigid behavior pattern.

Adults can benefit the five-year-old sibling of a child who is hospitalized by being available but not intrusive and by providing private places for the child to pull-together his or her own thoughts and emotions. We encourage parents to be honest with the child and admit not being able to understand the logic of it all. The child can tolerate this honesty better than answers which don't fit.

The School-Age Child. The school-age child is maturing. At this stage children are more cooperative and reasonable; their industry and ambition are reflected in an orientation toward learning and skills. School-age children look increasingly outside themselves for cues, look to peers for support and recognize that parents

are not infallible. The school-age child needs opportunities to make choices, opportunities for physical release and activity, peer support and team socialization.

By school age, children begin to view loss and separation realistically and to see death as final--struggling to keep a sense of control and autonomy despite feelings of fear and sadness. Sometimes they become overcontrolling and aggressive and may lose interest in peers. The school-age sibling may also over-identify and assume the role of the sick child in the family.

Adults are needed at this time for comfort and talk. Regression, in the form of assumption of behaviors appropriate for a younger child, should be acknowledged but not supported. We caution adults not to allow the child to assume too much responsibility (i.e., caring for parents, worrying about finances, etc.) at this time.

7 The Adolescent. The adolescent sibling is in a stage of contrast and ambivalence, neither a child nor an adult. Puberty adds new stresses to life; emotional and physical changes often are perceived as a loss of one's former self. Quick mood changes accentuate this seemingly irresponsible, irrational and inconsistent time of life; and adolescents often feel bad about their actions and emotions during these times.

As adolescents, they attempt to master many of the developmental tasks of childhood at a new and more mature level. They now must make sense out of the world, set realistic limits, learn that rules are not the same for all individuals everywhere, and learn to balance their own individual rights and the rights of others.

Adults can support adolescent growth and development by helping to acknowledge the child's ambivalence, supporting appropriate behavior, stressing the consequences for inappropriate behavior and providing opportunities for adolescents to try out their own values, within limits and within their own frame of reference.

Adolescents can think abstractly--can intellectualize about their thought processes--and may turn many of these thoughts inward. Although they often intellectualize feelings, they cannot process emotions. Loss and separation are felt deeply. Reactions of the adolescent may be at either extreme of withdrawal or acting out (from an "I don't care" attitude through the dramatic expression of confusing emotions).

The adolescent sibling of a hospitalized child also needs honest reasons and explanations provided by an unobtrusive but available adult. A supportive adult can help sort out emotions and plan constructive actions to deal with feelings. The repetition of clearly defined consequences helps curb the teenager's acting out while easing the weighty responsibility of total self-control. Group therapy is recommended if the adolescent becomes excessively withdrawn.

FEELINGS AND INFORMATION NEEDS

In addition to feelings of loss and separation, the sibling of a handicapped child must deal with difficult and complicated feelings toward friends, parents and the special child in the family (Cerreto & Miller, 1982). The appearance or strange behavior of the handicapped child may be a source of embarrassment, and siblings will probably have to learn to handle situations where they are teased or asked questions they cannot answer. They may be reluctant to bring friends home after school. As adolescents, they may be particularly sensitive about appearances in front of friends of the opposite sex. As young children, their peers are especially likely to engage in ridicule, and children will probably respond to their tormentors either with emotional upset or a backlash of anger.

Common concerns involving parents are the need for more attention, concern that the parents do not adequately discipline the handicapped child or feeling overburdened with household responsibilities. The literature shows that female siblings in particular are likely to accept more household duties and child care resulting in the curtailment of peer and after-school activities (Caldwell & Guze, 1960; Cleveland & Miller, 1977; Farber, 1959; Schwirian, 1976). Siblings may also experience feelings of neglect or unimportance due to parent preoccupation with the handicapped child's needs (Cleveland & Miller, 1977; Schwirian, 1976). When parents fail to provide information about or to discuss the handicapped child's condition, the siblings likely will express confusion and frustration. They probably will interpret their parents' silence on the subject as a command not to ask questions.

Children will have many feelings and concerns regarding the handicapped sibling in the family. They may have to cope with feelings of grief and loss of an expected sibling, similar to the process of parental grieving after the birth of a handicapped child. Such feelings are likely to surface when peers brag about their own siblings' accomplishments, (e.g., Little League). The adult grieving paradigm which has been used to help parents cope with the birth of a handicapped child (Solnit & Stark, 1961), can perhaps be applied to help children cope with these feelings.

Another broad area of concern is the sibling's understanding of the future of the handicapped child. Included in this concern are issues such as dependency/independency, vocational living arrangements and physical condition. Frequently, siblings are anxious to understand parental plans and may be worried about their own ability to cope in the event of parental death or disability (Schreiber & Feeley, 1965).

Older siblings are likely to be concerned that they may develop the same problem or produce children with similar handicaps. Such children will need periodic genetic counseling and information that meets the concerns of their particular stage of cognitive development.

Generally, children do not receive such information from hospitals. Though hospital professionals have adopted an educational framework to use with patients and parents, they have not applied this technique systematically to meet the

needs of siblings. Yet children in each stage of development do have needs for information about a handicapped sibling. Children in the eight- to ten-year-old group are concerned with functional aspects of their brother's or sister's condition. Their questions tend to be concrete: "What can my sister do? What can't she do?" They also need help to learn how to explain the sibling's condition to peers. Ten- to twelve-year-old children demand responses to technical questions on the etiology of the condition, and they should receive as much information as they request. Educational literature or brochures can meet this need. This age group too needs help explaining the sibling's condition, and role playing can be a very effective way to teach and rehearse such explanations. Adolescent siblings of handicapped children are more likely than younger children to be reticent about voicing concerns. When they do so, they likely will express sadness about their siblings' condition and anxiety about the child's future (Murphy, Pueschel, Duffy, & Brady, 1976).

A child's first need from professionals is for technical information concerning the handicapped sibling. Once the technical questions have been answered, the theme "Why me?" usually surfaces. At this point, it is useful to provide a supportive environment to help the child express ambivalent feelings toward the special sibling. Children frequently are confused and feel guilty about this ambivalence. Professional staff may encourage the child to recognize feelings of anger, embarrassment and sadness and should validate the normalcy of such feelings.

One common obstacle should be noted. Siblings often must balance needs for reassurance, expression and information with fears that they are betraying family secrets by seeking information or support from professionals. While leading a group for siblings of handicapped children, Kaplan (1971) found parents reluctant to allow their children to participate because of expressed concern over possible betrayal of family secrets. They felt it likely that children would provide a less idealistic picture of family life than parents would themselves present.

INTERVENTION METHODS

Most interventions with siblings will consist simply of providing the information or support requested. However, health care professionals will occasionally have to formulate an educational or supportive intervention or a behavioral plan of action to help children cope with their feelings.

Professionals should meet the children's needs for information or support at the moment and then encourage them to call or return when new questions arise. Children often need permission to seek information from professional staff and assurance that their questions are legitimate; they are often surprised to discover that staff are interested in the entire family and not just in the parents and the handicapped child. It may be helpful to provide a model for seeking information, by suggesting questions such as: What does the staff member do with my brother/sister during an appointment? What will my sibling be like in another year? Will my children have the same kind of problem?

Staff can also encourage children to use parents as information sources and to visit the handicapped sibling's school or intervention program and to ask questions. Concerns of young children may lead to mediation by professionals if the child consents. Older children especially can be helped to discuss concerns directly with their parents. The five steps outlined below can serve as a guide to successful communication between affected siblings and their parents.

1. Pick a time of day when parents are available and will be relatively undisturbed. Children can be helped to differentiate potential good times from potential bad times. Good times might include quiet time after dinner or a weekend afternoon. Bad times might include soon after a parent gets home from work or while the parent is driving in busy traffic.
2. Make a short, simple behavioral statement of the problem. Children, like parents, should be encouraged to avoid nagging and long, tedious monologues. Help the child learn to reduce the statement of the problem to one sentence: "Mom, I can't play baseball on the team because I have to come home to babysit John." "Dad, it's hard for me to bring friends home when Anita keeps bothering us."
3. Follow with an affective statement describing the problem's impact and the feelings involved. "I get really mad when you take Jimmy everywhere because he can't walk, and you don't have time to take me over to my friend's." "I could just cry when they call Judy names." "I don't think it's fair that I have to eat all the same stuff he does just because he has to have a special diet."
4. Offer a trial solution with an opportunity to reevaluate at the end of the specified time period. The sibling can suggest a plan: "Perhaps I could go to team practice on Tuesdays and Thursdays and maybe Grandmother could take care of Johnny on the other days. Can we try that for two weeks? If it works out, then I can play on the team. If it doesn't, then we can sit down and try to think of another plan."
5. End on a positive note. "Thanks for talking to me about this." "I'm glad we could sit down and talk about this."

Difficulties with the children's friends usually can be overcome when they can provide information to peers in a nonemotional manner. Staff can help by role playing with the siblings and encouraging them to use short, simple statements based on their personal understanding of the handicapped child's condition.

CURRENT PROGRAMS

Although formal programs for siblings are comparatively rare, programs are being developed. For example, The Sibling Network has been established through the Special Education Department at George Peabody College for Teachers of Vanderbilt University. The network provides for information exchange between researchers and clinicians attending to the concerns of the siblings of children with chronic conditions. Additional policy statements regarding the psychosocial and developmental needs of the siblings of hospitalized children are being distributed by the Association for the Care of Children's Health in Washington, D.C.

A formal program designed to attend to the informational and emotional needs of the siblings of handicapped children is being evaluated in the Galveston County, Texas school systems (Cerreto, 1978). Small groups of brothers and sisters of children receiving special education services meet three times a week for three weeks. The program uses tenets of social learning theory and structured learning therapy to teach siblings how to interact effectively and positively with their handicapped brothers and sisters and how to handle their own feelings in stressful situations. A number of products were developed. A children's workbook explains basic principles such as praise, ignoring and negative feedback to the siblings. An accompanying videotape presents common situations involving the sibling, handicapped child, parents and peers and stresses particular learning points in each vignette. The videotape depicts situations such as talking over a problem with a handicapped sister, working out a solution, and praising the sister for complying; ignoring a brother who is constantly bothering an older sibling doing homework; and explaining the sibling's handicap and behavior to a friend. A teacher's manual provides the program rationale, teaching guidelines and methods to encourage siblings to role-play the situations. The program products are being evaluated for use with eight- to ten-year-old siblings of mentally retarded children from multicultural backgrounds.

The health care/education relationship is a collaborative effort vital to the needs and concerns of the siblings of hospitalized and developmentally disabled children. Rewards are evident in statements by older siblings of the very positive effects of having a handicapped brother or sister: "Learning to understand Gerry sure makes it a lot easier to understand people who are different from me in other ways too, like in color or religion." "I sure have a lot of patience!" "After you worry about really serious stuff with Debbie, you don't get upset with a lot of little things." "We seem to talk about a lot of things that other families don't." The integrative effect of the presence of a mentally retarded child on the family is noted by Robinson and Robinson (1976). And higher levels of empathy and altruism are noted as characteristic of the siblings of handicapped children (Grossman, 1972). Our programs must be designed to build on the potential positive aspects of being the "special sib of a special child" and to improve attendant problems. With the inclusion of the sibling, our range of supports is truly a family approach.

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CLINICAL REALITIES OF THE ATTACHMENT PROCESS

Richard Iacino

This paper attempts to characterize clinical realities associated with facilitating attachment between mothers and their hospitalized newborns. Since the issues under discussion have been generated out of clinical experience and small pilot studies rather than well-controlled trials, it is appropriate to approach this topic with some wariness. However, there are two impelling reasons to raise these issues despite the modest data base. First, these issues directly affect the formulation of intervention strategies. Second, only by acknowledging that these persistent, vigorous and somewhat troubling clinical realities exist can they be brought into focus to develop workable protocols for scientific investigation.

This chapter will address four general issues: the appropriateness and utility of the concept of bonding; the possible effects of differing cultural backgrounds on the attachment process; the utility of delayed bonding as a parental coping mechanism; and the potential for competitive attachment between parents and medical care staff.

These issues grew directly from ongoing attempts to develop, implement and evaluate an intervention program, based in a fairly unique neonatal intensive care unit (NICU) setting at Jackson Memorial Hospital in downtown Miami. The NICU serves people from a variety of cultural and ethnic backgrounds. Staff communicate with parents in a mixture of English, Spanish and Creole French or, in the absence of translators, by much gesturing and smiling. Many of the families are first-generation immigrants whose legal immigration status is in question. There is true cultural diversity, since most of the families have had little time to adapt to the American mainstream. The project serves a large, urban, multicultural population skewed to the lower end of the socioeconomic range.

Issue 1: For the interventionist, how appropriate and useful is the current concept of bonding?

A critical look at the literature on mother-infant bonding (Osofsky, 1979) raises some genuine concerns about current conceptualizations of the topic. The most vigorous proponents of bonding leave readers with an impression that it is

almost a physiological process and that it has critical periods for development. Morgan's (1981) and other reviews of this literature, however, raise questions that make this type of conceptualization difficult to defend. Yet, when one works with many parents of newborns, observes their changing response to their infants, and listens to their feelings and perceptions, one does perceive the reality of an attachment process.

The notion of a "constellation of attachment behaviors" rather than the overextended concept of "bonding" might have real utility for intervention programs. First, dropping the term "bonding" might renew the interest of researchers and physicians who have had difficulty accepting the internality and overextension of the early research. Second, it would allow researchers to identify constellations of well-described behaviors which could be studied to determine their existence, sequencing and importance in initial or long-term development of the infant and family unit. This, in turn, could help interventionists pinpoint more accurately the focus of their family intervention efforts. Essentially, the notion of a constellation of attachment behaviors would allow for the description of widely varying patterns of attachment, the study of their usefulness in a given family structure and, most important, the determination of the appropriateness of intervention.

The utility of this alternative concept of the attachment process is apparent in the discussion of the following issue.

Issue 2: Do differing cultural family backgrounds significantly alter the constellations of appropriate behaviors?

As part of the overall evaluation of the effectiveness of the Jackson Hospital project's intervention services, a sample of infants and families is being followed on a longitudinal basis. The study is using matched pairs of families, divided into intervention and control groups. Since they were assigned randomly to the study, there was no control on the cultural and ethnic background of the families.

Results have varied during the course of the intervention. While this is not unusual, there was a group of families with whom we had a noticeable lack of impact as we tried changing their behavior to that which we considered appropriate, or indicative of attachment (including visitation frequency, quality of mother-infant interaction, expression of appropriate attitude, etc.). We noted that most of the families with whom we had both the least and the most impact represented particular cultural groups. While there may be competing hypotheses as to why this occurred, it seems that mothers of different cultural backgrounds vary in their constellation of attachment behaviors. A sample of medical care staff impressions of typical visitation patterns by particular cultural groups showed remarkable consistency. These clinical impressions are strong enough to suggest a hypothesis that attachment behaviors may depend on the family's cultural and ethnic background and that we may need to tailor intervention strategies accordingly.

Issue 3: Can a delay in forming mother-infant attachments be useful as a parental coping mechanism?

The delay of bonding, or in our suggested terminology, the delay in showing certain constellations of attachment behaviors, often has been postulated to be a coping mechanism (Klaus & Kennel, 1976). Delay in bonding is often seen in relation to parents' perceptions that their infant may die. Parents of a critically ill infant might believe that by delaying attachment to the baby they will limit their subsequent grief. Our own clinical experience, however, suggests that this is not the case. The grieving process remains as intense and often more so--due to an increased sense of guilt--for parents who limited their contact with their critically ill newborn.

Low socioeconomic status appears to be another factor associated with parents who delay attachment. Some low-income parents clearly do not believe that their hospitalized infant will die. In fact, in many instances these parents correctly assess and express that the infant is healthy, the prognosis excellent, and their time line for discharge is fairly predictable. But these families' daily lives are often a constant exercise in crisis intervention, with little time or effort and few resources available for prevention or planning, except for the most pressing problems. The birth of a child into this type of family is often unplanned and sometimes undesired. Since the infant is well cared for in the hospital--and perhaps the parents perceive that care to be better than they could provide at home--this particular crisis is relieved of its urgency. This respite allows the problem to take lower priority on the list of imminent crises until such time, usually approaching discharge, when it will once again claim its place at the top of the list.

A mother in this situation may react "appropriately" while she is interacting with her infant (she appears to have acceptable perceptions about herself and her infant) yet may not contact or visit the unit for days at a time. This type of parent often subtly erects roadblocks that delay discharge of the baby. Developing appropriate intervention strategies for these parents has been difficult. It may appear that the intervention focus should be to increase the frequency of behaviors that already exist, that is, to encourage more visits to the infant. But such an intervention strategy demands more of the parent's time and attention to the newborn and so keeps the baby high on the list of problems and requires the family to expend more of their limited resources.

Our project staff think this might be an inappropriate goal for a family support service. If a mother behaves appropriately with her infant but has other legitimate and serious demands on her time and efforts, it may be inappropriate to target standard family intervention for her. Developing individualized constellations of attachment behaviors that reflect the realities of family situations seems a more worthy focus of intervention efforts.

Issue 4: How might attachment behaviors developed by the medical care staff within a unit affect the attachment process of the parents?

In an NICU, one sees concrete evidence of attachment between the medical care staff and the infants in their charge. Despite the best medical care, the death of an infant is a common occurrence in a special care nursery, and these occurrences affect medical care staff on a very personal level. NICU's are tough places to work, and high staff turnover is a problem for all hospitals. Strategies for minimizing the negative aspects of this type of work would be valuable.

As part of our project efforts, we are studying how and to what degree nursing staff attach to infants in their care, how this attachment competes with or facilitates parental attachment, and how such attachments affect job perception or performance. Early results of a small pilot project point out some interesting trends which we feel should be pursued further and in more controlled studies. First, by self-report, nurses almost always have a favorite infant in the nursery. This infant is not always one for whom they have primary care responsibility; more than one nurse often reports the same infant as a favorite. When asked to rate the degree of attachment to the favorite, nurses usually report only moderate attachment; strong attachment is rarely reported. Though not limited by the reporting system, nurses seldom identify more than one favorite at a time, and never more than one for whom the degree of attachment is rated as strong. Self-rating of a nurse's degree of depression over the removal of a favorite from her care, either by death or transfer, was also solicited. Nurses reported being more depressed over the transfer of a strongly attached infant than they did over favorites who died.

Though more formal work needs to be done in this area, our pilot study indicates that 1) self-reports of attachment by nursing staff are generally reliable and 2) there may be some correlations between the outcome of the infant and the mood of the care staff.

Also of concern to us are instances of what could be termed competitive attachment between nursing staff and parents. Sometimes, a nurse verbalizes negative evaluations of the skill and concern she perceives in the infant's mother. This may be inevitable in situations where the nurse has attached strongly and perceives that the mother is not meeting her obligations. As long as this evaluation remains private (or limited to social service staff as part of referral for parent intervention) the effect is probably not damaging. However, if this type of situation develops into a competition between mother and nurse, the potential for damage is great. Family intervention staff should be prepared to identify and work with nursing staff and parents to resolve such situations.

SUMMARY

This paper has described some clinical realities which should be addressed as part of an effort to develop, implement and evaluate a family and neonatal infant intervention program within a large, urban, multicultural, special-care newborn nursery. The issues raised are clinical impressions supported only by pilot data. But they suggest interesting phenomena to be investigated with greater control in order to detail the exact characteristics of the problem and to indicate potential solutions.

The tentative initial results of the clinical experience and small studies suggest some recommendations for the interventionist faced with implementing a program:

1. A concept of a constellation of well-described attachment behaviors is more useful in a research or intervention focus than the ill-defined and often overextended concept of bonding.
2. Developing constellations of attachment behavior requires acknowledging typical behaviors exhibited by various socioeconomic or cultural and ethnic groups.
3. Intervention goals must take into account the real-life situation of the family and infant. Interventionists must be careful not to impose values or demands on parents which are not useful to the families' lifestyle or not required for appropriate developmental progress of the family unit.
4. Attachment by medical care staff to infants in their care is a very real phenomena. In rare instances, competitive attachments between care staff and parents can develop. Interventionists must be prepared to recognize and resolve such problems.

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COMMUNICATION STRATEGIES WITH PARENTS

Ronald J. Schmerber

Effective communication is a necessary and important component of any family support program for families of preterm and high-risk infants. Yet in the stressful setting of the intensive care nursery, open and effective communication between parents and staff can be very difficult to achieve. A hospital is thought of as a place where people should get well, where there are answers. With preterm or high-risk infants, however, progress is often slow, with many ups and downs and crises and, most of all, few immediate answers. This creates a situation where families and staff easily become frustrated and tensions run high. In such an environment, a traditional, therapeutic approach to families; where health care professionals are seen as objective, impersonal authority figures, may be inappropriate or ineffective.

At the Pre-Start Program for families of preterm and high-risk neonates in Maywood, Illinois, we have set aside traditional conceptions of the professional role and addressed some fundamental questions: What factors are necessary to create open lines of communication in a crisis situation? What are the concerns of the families we are dealing with? What do they need? What can we, as professionals, do to encourage effective communication and meet family needs in this area?

Our answers to those questions and our experiences in the neonatal intensive care unit at Loyola University McGraw Hospital, have led us to formulate a new conception of the professional role in family support and a new, personal-response approach to parent-staff communication. We have found this approach to be more important than technique or style. To achieve it requires more than interviews or agendas. It involves a willingness to look at ourselves and the families we are serving in new and sometimes unfamiliar ways. This chapter outlines the Pre-Start approach and some of the thoughts and experiences which have led to it.

THE PRE-START APPROACH

The key to successful communication is the understanding that people are the most important element. It is important to keep in mind that both parents and professionals are people first and only secondarily the players of their respective

roles. We are all individuals with our own vested interests, biases, and prejudices; we have ups and downs; we can share closeness, create distance, build temporary or lasting relationships. Who we are and what we want to do makes the difference.

At Pre-Start, we try to create an attitude and atmosphere that easily permits open communication. We strive for a warm and open environment in which parents can share the often frightening and unfamiliar thoughts and feelings which accompany the birth of a preterm or high-risk child. We work to achieve this by listening and responding to families in a natural and informal manner, an attitude of action and word which says to them, "We will search together with you, let you be yourself and help you feel comfortable and safe by being yourself with us." We attempt to be available without forcing ourselves on the family, to "create enough space around us so that people can feel our presence and yet, at the same time, feel free within it" (Kennedy, 1977, p. 150).

Our goals include: a feeling of caring and being cared for; a nonjudgmental exchange of information and ideas; freedom to share thoughts, feelings and ideas while emphasizing trust, acceptance and safety; a warm and accepting atmosphere; opportunities to feel and think; opportunities to relax and take a psychological, emotional, or physical break from the hospital setting. Our policy is to provide assistance without interference, to emphasize the value and safety of being oneself and relating as best as we can.

There has been no attempt to impose a therapeutic model on our communication. Pre-Start staff members function as resource people, and they try to be genuinely interested in developing mutual respect and trust. The Pre-Start Program is based on a philosophy of partnership with parents, of emphasis on parents' competencies and growth. Our focus is not on the mother, the father or the infant, but on the family system, and we treat that system with great respect.

THE RESPONSES OF PARENTS

To work effectively with parents of preterm or high-risk infants, professionals must begin by understanding and accepting the family's reality. They must realize that the experience of having a baby in the intensive care nursery places tremendous stresses on parents--physical, emotional and financial stresses which profoundly disrupt their lives.

It is not uncommon, for example, to hear parents state that their own needs are not being met, or are at the very least being threatened. These unmet needs, as viewed in Maslow's (1970) system, include physiological needs, needs for safety, for love and belonging and for self-esteem. For example, parents sometimes neglect the simple physiological tasks of sleeping and eating for two or three days at a time while at their infant's bedside. Their safety is threatened with anxiety, chaos and fears. The intense focus on the condition of their child may cause parents to sense a loss of belonging. This, in turn, can have the effect of lowering their self-esteem. Parents may find it difficult to express themselves, do as they wish and maintain order in their lives. Many ordinary concerns of daily life

become intensified, and some of the routine decisions become very difficult. The intensity of the situation, the many different people they must relate to continually, the many adjustments that must be made, often at a moment's notice, and just being in a very unfamiliar place without much preparation, can be disruptive to normal thought processes. Parents often have trouble making adjustments. Their coping and defense mechanisms are greatly taxed. Some concerns often mentioned by parents include:

Job. Minor or major disruptions, periods of time without pay, catching up, fear of being fired, not really attending to job tasks.

Issues of Life and Death. Often, this is the first time this issue is confronted by either parent or by the family system. Questions include: How will the parents survive the death of their infant? What will they do if the infant dies? What about funeral arrangements? What kind of religious or burial service would be required? How would they tell others?

Single Parenting. What support systems are available? How will the parent deal with family or friends? Money issues: Who will take care of me or my baby? Should I keep my baby?

Fear of the Unknown. Did I cause this problem? What did I do to make this happen? What will my baby be like? Will my baby live? Who will help us?

Siblings. How will I tell my other children? How will they react? Who will take care of them when I visit my baby? How much should I involve them?

Financial Concerns. What are the costs of hospitalization? What are the additional costs incurred for parking, phone bills, miles driven and gas used to visit the infant in the hospital? What is the insurance coverage? Is there enough? How to handle the discrepancies between the hospital's charges and the insurance company's payments?

Feelings. Noticeable differences--depression, irritability, loss of appetite, tension, argumentative at times, aloneness, feeling that nobody understands. How do I tell others? How much do I tell others?

These stresses are heightened by the physical, mechanical and emotional separation of parent and child. Often the mother is in one hospital while the child has been transported to another hospital miles away. Parents may have to travel great distances to visit their infant. Even within the hospital they sometimes cannot get close to their child because of all the tubes and devices needed for life support. Parents say that all of this distresses them and gives a sense that their child may not belong to them. It creates an atmosphere where closeness and attachment are hindered. There is often a cautious involvement when parents visit the special care or intensive care nursery.

Different individuals may respond to these stresses in different ways. Benefeld, Leib and Reuter (1976) have found that parents of preterm infants may experience feelings of anger, guilt, irritability, sadness and a need to be left alone. They often react with difficulty in sleeping, with prayers and with fears that the baby might die. (In fact, the responses are similar to those of parents whose infants have died.) Similar reactions are revealed in the comparison by Taylor and Hall (1979) of the responses of parents of full-term and preterm infants (Figure 1).

Figure 1

Parents' Usual Emotional Reactions and Adjustment to Full-Term
and Premature Births--Some Contributory Factors

	Full-Term Delivery	Premature Delivery
Perceptions of event	Gain, success	Loss, failure
Reactions to birth	Joy, relief	Grief, concern
Emotional preparation	Complete	Incomplete
Expectation confirmed	"Wished-for" baby	"Feared" baby
Self-esteem	Increased	Decreased
Baby's primary caregivers	Mother, father	Nurses, doctors
Parents and infants	Together	Separated
Baby's social responsiveness	Well-developed	Decreased or absent
Mother goes home with:	Baby	Empty arms
Major psychological tasks remaining	Reconciling real baby and fantasized baby	Grieving for expected baby; anticipatory grieving for baby; individualizing and accepting baby

Note. Reprinted with permission. Taylor, P.M., & Hall, B.L. Parents usual emotional reactions and adjustments to full-term and preterm infants. Seminars in Perinatology, January 1979, 3(73), 73-89.

MEETING FAMILY NEEDS

In their studies, Benefeld, Leib and Reuter (1976) found that an organized family support program was helpful in maintaining family stability. To be effective, such programs must maintain a focus on what is important to the parent. They must offer support without trying to force thoughts or make parents feel they "should" be feeling certain things.

Many families have said that this was critically important to them. At a time when they felt most vulnerable, they greatly needed someone with whom to share their thoughts without being judged. As one father put it, "It was good to have someone listen to me when I needed that and not feel there was something special they had to say, or I had to say. I could just be myself--that's what I needed." Another parent spoke of the importance, and great difficulty, of sharing thoughts which she considered unspeakable. When she felt safe to share them, she was greatly relieved to get them out.

Duff (1981) has pointed out that families need to hear a clear message that staff will try to serve their interests and stand by them through thick and thin, through all the ups and downs, that they will not run away and leave the family alone when times are rough.

For professionals, the most important idea is to join respectfully with parents in the search for what is happening in their lives and to help make the best possible sense out of it. Parents are surrounded by an unfamiliar environment full of people and machines, and the professional may never really know exactly how they think or feel. The best we can do is to listen and respond and try to understand the direct and indirect messages. We need to listen without projecting our own feelings on the parent. It is important to be as close to families as possible--emotionally, physically, mentally--without creating a sense that the professional has all the answers. The valuable message is that someone is there and ready to respond.

Many things can help project this message. Parents have stated that a simple statement such as "How are things going?" or "How are you today?" opens many doors and gives parents permission to be themselves. For example, fathers have noted how difficult it can be going from one hospital to another, taking care of finances and other children, bringing information back and forth to the mother, and generally going it alone for a while. Some feedback has shown that a comment like, "You know, sometimes it may be harder on the fathers" can go a long way in letting fathers know they have needs too, and that someone cares for them as well as the mother.

It may help to identify possible feelings, such as being mad, sad or scared. Saying to a parent, "Sometimes this can be a scary place" may provide the opportunity for them to identify with the feeling and respond. It is important to let parents know that their thoughts are quite normal, healthy and necessary to help them adjust to the situation.

It is important to allow time for parents to work out their feelings. There is need for alone time and together time. Time is needed to develop trust, to search for options and to think and act. Time is so important, but it must be quality time. Sometimes through a simple statement such as "Think about this for a while" or "Let me know when we can share ideas", the parent knows that the professional respects their own time demands.

THE TASK FOR PROFESSIONALS

Many people enter a parent's life after the birth of a preterm or high-risk infant. Doctors, specialists, nurses, social workers, counselors, clergy, residents and interns, and perhaps even medical students contact families, either intentionally or not. Each one must be sensitive to the family's immediate experience. To do this, professionals must understand what it means to them to be available to parents. They must understand their own attitudes, limits, fears, doubts and beliefs.

It is important to recognize that there may be no cures or answers but just opportunities to be there and join parents in their struggle. Professionals must recognize the strengths of each person working with the family and also accept that there might be limitations on what we may or can provide. They must be willing to ask themselves questions such as: Why am I involved with this family? What can I do to help? What might I do that could hurt? What are my strengths? What are my weaknesses? Do I need to consult someone else? Can I tell a parent, "I don't know?" Can I ask, "What can I do to help?" or, "Can someone else help you better?"

Control. As professionals, we must be willing to examine our attitudes toward control. It is very difficult to control a crisis situation, but this is precisely what many professionals try to do. Many things are important in a crisis situation, the most important of which are the people involved. To have an agenda or specific technique would be to impose a structure when it is not needed. The consequences can be detrimental; it is very easy to foster a sense of helplessness in parents by doing too many things for them. It is easy for nurses to make name cards for the infants, or to clean and care for them, or bring in little stuffed animals. But these actions tell the parents that they are not needed. When parents were able to make their own name card, clean and care for the baby or ask their questions and have the staff respond, they became less tense, more involved and active with the baby; and they better understood and dealt with their situation. As one mother described it, "Finally someone let me do something. I'm not helpless, you know, and I don't want to take over. I just wanted to be able to do something for myself and my baby."

The secret of interacting and communicating is to be a resource, not a protector. When professionals realize that their power may be limited, some control of the crisis can be transferred back to the family. The task for professionals, then, is to identify their own need for control, know when they may not be needed, and to suggest options for the family, instead of making decisions for them. Counseling then becomes a process of doing something with the family instead of for them.

Family competence. Each family can do something positive about their situation. As professionals, we need to help families understand how they can cope and succeed despite the odds. McCubbin, et al. (1980) have noted four basic factors

which affect families' ability to manage stressful situations: family members' personal resources, the family system's internal resources, social support and coping.

There is much that can be done to help the parents keep a sense of competence and importance. Professionals can give cues in a natural manner which grants parents permission to share feelings and thoughts together with us as partners, in a way that does not permit the parent to become identified as a patient or as the one with problems that the professional must solve. "Little things", such as taking pictures of the baby, keeping a photo album of progress, having siblings send items such as pictures or toys, obtaining free parking, providing contact with other parents who have had a child in an intensive care nursery can all have a great and welcome impact.

Perspective. Keeping perspective is important. Parents may be difficult at times due to their anger, guilt or sadness. It is quite typical for staff to become fed up with a particular parent, to become tired of the endless questions or to feel frustrated because not too much progress is occurring medically for the infant or emotionally for the parents.

Professionals should be aware that parents often do not sleep or eat, and they have fears which, although they loom large for the parents themselves, may seem trivial to staff. Scalp intravenous's pose a good example. To the staff, the insertion of an intravenous feeding needle in a scalp vein is a relatively common and simple procedure. To parents, however, it may seem a serious and frightening surgical operation. The hair is shaved at the spot where the needle is inserted; the needle is held in place by tape, and often protected by a patch. Some parents have reported they were fearful that hair would never grow over the spot again, that the needle would pierce the brain, that there would be permanent scar tissue, that it was an indication that their infant was dying. Some parents become hysterical at the mention of this feeding procedure. We have two perspectives of the same event. Each must be respected and understood.

Respect. To work effectively with parents, professionals must respect each family system as individual and unique. Perceptions need to be checked out to see whether they apply to the situation as it exists or if there is some intended meaning of another situation. For example, one parent recently was extremely anxious about having a child with Down's syndrome. Later informational discussion revealed that two families, each with a Down's Syndrome child lived close to him, and his previous fears had now become reality.

The helping process should always include privacy and respect for each family's situation. Nothing can do more harm than a breach of confidentiality or respect for the family's views and situation.

Honesty. We have found that professionals' best tool or technique for working with parents may be to present themselves as honestly and openly as possible. Parents have mentioned that the way a nurse handles their baby, how a person drawing blood from the baby talks to the baby and parent, how parents are greeted or have their questions answered indicates how personally their child is

being cared for. Parents quickly equate this personal care for them and their infant to the quality of general medical care given to their child. (No wonder, then, that professionals who provide care for the infant must provide care for the family.) There can be no room for excuses. Parents recognize the excuses, and in most instances, silently reject them. As one parent poignantly stated, "Nobody can fool me. I know when they are not being honest. When it is your child a parent knows. A parent can tell who is sincere, or who is just doing their job."

SUMMARY

The Pre-start program is a new approach to working with families, based on a personal response model. Hoffman (1981) points out some key policies of this model: don't spend time trying to find causes for the problems; maintain a positive view of the crisis issue; don't rely on negative interpretations; look to the total context of the situation, not just specific aspects which are often negative; don't attempt to be in control but facilitate growth based on family needs; allow time for change by not spending too much time on past or future issues; and recognize that unpredictability in stressful situations is often beneficial and necessary.

Professionals working with families of preterm or high-risk infants must develop a trusting, caring partnership, without worrying about style or technique. The ultimate goal may be to allow a level of comfort to exist in an environment that is inherently uncomfortable. Perhaps Milton Meyeroff (1971) set the tone for our work with parents by stating, "In the sense in which a man can ever be said to be at home in the world, he is at home not through dominating or explaining or appreciating, but through caring and being cared for" (p. 2). The essence is to care--all the rest follows.

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